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**The Loss of a Child:
The Long Term Impact upon the
Parent - Child Bond**

by

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B.Sc.(Hons.) M.Phil.**

A thesis submitted in fulfilment of the requirement for
the degree of Doctor of Philosophy in Psychology

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DECLARATION

This thesis contains material from a previously submitted thesis for a M.Phil. in Theology. This was titled, 'Bereavement in Families who have lost Babies, Children, and Teenagers; An Empirical and Theological Study.' Birmingham University, 1995).

This thesis also includes material previously published in the book, *Suffering Love*, by Bill Merrington; Advantage publishing, 1996.

Both materials have been reworked and have undergone change from a theological to a psychological perspective.

This thesis is the candidate's own work, and has not been submitted for a degree at another university.

SYNOPSIS

Research has been carried out from a psychological perspective, to examine the effects of bereavement in families when they have experienced the loss of a baby, child, teenager, or young adult. This has involved interviewing parents in Lebanon, Tanzania, and Uganda. The results were then compared to previous research carried out by the author in England (For a M.Phil. in Theology titled, 'Bereavement in Families who have lost Babies, Children, and Teenagers; An Empirical and Theological Study.' Birmingham University, 1995). Using the collective data, the theory of Shadow Grief is investigated in terms of whether it is a genuine condition within bereaved parents, as compared to other grief reactions such as chronic grief, disenfranchised grief or pathological grief.

It was found that the bond between a parent and child was a particularly deep rooted affectionate bond. There are similarities between this bond and Bowlby's concept of attachment theory. Parents from the English sample showed some signs of maintaining a bond with the deceased many years after the loss. This was seen to a lesser extent in the African context. This requires further research to clarify this effect both in the English culture and cross-culturally, looking at a broader section of communities where child loss has taken place. Grief therapists need to be more aware of the long lasting effects that the loss of a child has upon a parent, especially those who are bereaved of older children.

CHAPTER 1

INTRODUCTION

This chapter outlines the background to the reason why the author has investigated the effects of bereavement in families who have encountered the death of a child.

As a child of six years of age I recall seeing my grandmother ill in bed in the family's living room. She had cancer and both breasts had been removed. I recall seeing her scar tissue as I played by her bedside, and I can remember the smell of morphine that the nurse brought daily. I have a clear picture of the night my grandmother died and the following day seeing her in the coffin in the dining room. Years later when I was a young adult, my mother died of the same illness in the same position in the living room. Both memories are lucid to me if I choose to recall them, however they conjure up little, if any emotion within me. What is left are fond positive thoughts about my relationship with both women. The loss of a mother and a grandmother has obviously had some influence upon me. In the immediate months following the loss, I suppose I encountered grief and mourned like most children who loose parents. But now years later, the effect of the loss seems to only influence me if I allow myself to recall old memories. It feels rather like a book that has been read and now is placed upon a shelf to gather dust. I can retrieve the book and blow the dust away and reread the moments of the past. But as far as daily life is concerned the book appears to have little influence upon me.

Years later as a chaplain in a maternity hospital I would often be called out to care for parents about to experience the death of their baby. Entering the neonatal unit there would be the sound of machinery labouring to keep alive, almost lifeless forms. The noise as well as the sight was frightening to the uninitiated. Complicated looking equipment would surround the individual and created an intimidating picture: tubes, intravenous bottles, wires, drainage jars, oscilloscopes, heart stimulators, blood pressure monitors, and respirators. Homing in on one baby born prematurely, I would see a child weighing only three pounds, with plasma and glucose drips going into both tiny arms, oxygen being fed into both nostrils and a respirator tube down the throat of the child creating an unnatural appearance. A blood pressure cuff upon the baby's would be feeding results to a digital monitor next to the cot. Electrocardiogram patches would dot the baby's little chest and a little gauze pad covered the eyes. The room was full of buzzing, hissing, wheezing, thumping noises of the support machine and standing close to the baby I would hear the air being pushed into and extracted from the lungs by the respirator. Having been called to the ward it would be obvious which incubator to go to as it was surrounded by people. My role in all of the confusion of the machinery lights flashing and beeps being emitted, was to take the parents to a sideroom while the nurse removed the hi-tech equipment from the baby. I would quietly listen to the parents story while out of sight the nurse put some doll clothes on the baby and lifted the child into a wicker basket. As the baby was brought into the room I would be left alone with just the parents and the almost deceased baby. I would encourage the parents to pick their child up and hold him fully, perhaps

for the first time. Silently we would wait for death in the midst of tears. Sometimes the father would find this all too much and dash outside for some fresh air. An hour or two later the parents would leave the hospital without their baby and I would go home to my family. As this occurred time and time again I could not stop wondering how these parents coped going home into a community that was expecting a new life to be present, facing relatives who perhaps had never seen the baby, and explaining the events to other children in the family. This seemed such a contrast to my own experience of death and loss.

As a clergyman in the church of England I later experienced visiting families who had experienced a cot death within their home with all the trauma that went with such an event: the call of the ambulance and the arrival of the police who had to respond to potential cot death occurrences, with the suspicion that the death may not have been by natural causes. It was obvious that such losses were leaving parents and families in a state of turmoil with potentially long term problems. I also had to deal with funerals of older teenagers and with supporting parents experiencing a whole host of emotions from despair and anger to feelings of wanting to commit suicide.

Every day in our newspapers and on the TV news we learn that someone somewhere has died. Be it here in the United Kingdom, Rwanda, Kosovo or the Middle-East, or wherever through accident, illness or old age. Death is part and parcel of life.

However, the death of a child makes society pause in shock. We reacted with horror

at the murder of Jamie Bulger, and suffered with the parents of the children who died in the M40 minibus accident. We followed every moment of the search for three-year old Rosie Palmer, who disappeared when she went to buy an ice-cream. We watched the hunt for the murderers of seven year old Sophia Hook, who was kidnapped from the tent in her Uncle's garden, and fifteen- year old Naomi Smith who was murdered in a playground as she went to post a letter. Similarly, the nation stood still at the news of the Dunblane massacre, and through the campaigning of Leah Betts's parent's we were reminded of the impact of the loss of a daughter through taking an ecstasy tablet. We saw the reaction of the public with large quantities of flowers for the death of Sarah Payne.

The high profile that the media gives to violent deaths may seduce us into thinking that childhood deaths are rare. Sadly, that is far from the truth. Whether it is the loss by miscarriage of a baby, a cot death, a child dying from leukaemia, a teenager killed on a motor bike accident, or a parent losing a thirty five-year old son, the fact is that thousands of parents experience the death of a child.

Observing the traumatic nature of the loss of a child of any age raises many questions of the nature of grief and whether there are unique factors at play when it comes to the loss of one's own child as compared to a grandparent or parent. What differences are there between parents when they lose a baby as compared to a teenager? And what are the long term affects of being separated from a child?

Are there unique factors in the relationship of a parent with it's child that complicate the grief process?

This thesis seeks to look into the parent to child bond reflecting upon the impact this bond has upon parents through the years that follow their bereavement.

Fred and Violet were a typical couple with two children. Alice was sixteen and still at school and Alan was twenty and studying theology at university. Alan was deaf in one ear and he coped with this admirably. He was a tall, handsome, blonde-haired young man with a marvellous future ahead of him. Term had just finished for Alan so he was on his way home for the summer holidays.

As Alan stood on the platform at the railway station, he didn't hear the train coming as it rushed through the station. He was standing too near the edge and the train caught his side. His parents reached the hospital only seconds after Alan had died. His face was unmarked by the accident and Fred and Violet sat with him holding his still warm hand.

Fred and Violet were not new to bereavement. They had both lost brothers in the war and their grandparents were dead. Alan was the same age as the uncle he was named after, who had died in the war. The events of the following days were a blur to Violet, except that she could remember how beautiful and at peace Alan looked in hospital. Her parents came and took over all the necessary arrangements. Violet resented this intrusion. Life was a strain as she and Fred tried to continue with their lives.

"For the first three years if I saw a tall blonde person I would look intensely to see if it could be Alan. It all seemed false somehow, rather like living in a bubble. I was not suicidal, but I was extremely angry with God. Some of our friends were helpful, but most didn't have a clue what it was like. One even invited us to watch a film about a train!"

Violet ended up in hospital with what turned out to be a minor problem, but eventually recovered, physically at least. Alan's sister Alice felt neglected in the months afterwards by her parents. She had been especially close to Alan, remembered him by playing his tapes over and over again, but she never talked about him. Alice had always wanted to study medicine but suddenly changed her mind. Eventually she changed her mind again and became a doctor. She fell for a handsome man, just like Alan, and the happily married couple had a baby boy. But then Alice suffered for nine years with cancer before she died.

Once again, Fred and Violet had nothing to organise as their son-in-law dealt with all the arrangements. Alice's husband wanted a quiet funeral, afterwards he kept himself and his son away from the grandparents. Fred and Violet had not been given any possessions belonging to Alice, so had nothing to remember her by. For Alan, Violet could picture how peaceful he looked, but Alice had fought such a battle with her illness that Violet could only recall an awful sight.

It was thirty years since the loss of their son when I interviewed the couple. They expressed how they felt they had nothing really to live for any longer. They rarely saw their grandson, and in retirement with so much time on their hands they found it

hard not to dwell on the past. The deaths had created a sort of distance in their marriage, a constant strain between them. Not long after Alice's death, Violet found herself once again in hospital.

"I was in shock for a long time after Alan died, whereas for Alice I knew it was coming, although it affected me just as deeply. The only thing I have left now is Alan's ring."

This couple's story is not an unusual one. The question that they asked themselves was whether what they experienced was any different from other bereaved parents. They themselves would recognise that the loss of children seemed to have a far greater impact upon them as compared to other losses that they had experienced. In the next chapter I will trace the backcloth to our understanding of grief to see how well it relates to the loss of children.

CHAPTER 2

HISTORICAL SURVEY OF GRIEF

This chapter provides an historical background to the study of grief. It specifically contributes to our understanding of grief by drawing together research material on the effects of child loss. This is conveyed by looking at the historical development of our understanding of grief, modern theories of grief, and the specific effects of child loss.

HISTORICAL INTRODUCTION

The death of a child is currently considered to be the least natural of deaths (Rees,1997). A theme that emerged from a contemporary study of infant death was the belief that at some time in the past, when infant death was more common in the west, the loss of an infant was not as devastating (Gilbert & Smart,1992). Recent research has examined grief and mourning across cultures and time, concluding that the outward expression of grief, and perhaps even the feelings themselves, vary across culture and history (Stahl 1991; Stroebe, Gergen, Gergen, & Stroebe, 1992). When Stahl interviewed Jewish women in their 70s and 80s who were born at the turn of this century, he found that they had been taught that the death of a child was God's will. When they lost their child they did not recall feeling much grief. However some still felt such emotion that they wept during the interview. This suggests that perhaps the loss of a child did have deep long term consequences.

From Smart's (1993) review of parental bereavement in history, there is evidence that in the 1600s and mid-1700s in England and the American colonies, parents did feel grief when their children died. She quotes Pollock who focused upon 17th century parent-child relationships. Pollock reviewed five hundred diaries and autobiographies and found records of parental grief following the death of a child (Pollock, 1983). She concludes that the basic feeling of loss is universal, but it's expression reflects the contemporary culture.

From the mid 1700s until the end of the 1900 century, sentimentality about the family, death and grief took hold and grew in influence. As the Victorian era progressed, preoccupation with grief came into full bloom and then withered. From the late 1800's until the 1960's grieving was a taboo topic (Gorer, 1965). Gorer's argument was that death as a taboo subject was replaced by sexuality until 1960's, when an increase of interest took place resulting in varying views of bereavement and grief.

REVIEW OF MODERN THEORIES OF GRIEF

The professional view over the last few decades is that the bereaved must grieve in a particular way, or face dire psychological consequences (Wortman and Silver, 1989).

The twentieth-century modernist view is that systematic grief work restores the mourner to a normal, almost pre-bereavement state (Stroebe, Gergen, Gergen, & Stroebe, 1992).

FREUD'S CONTRIBUTION

Freud's influential paper, 'Mourning and Melancholia,' was a serious reflection upon the effect of the loss of a love object (Freud, 1917). Freud saw grief as a painful state of mind. Using the theme of economics, he treated grief as a psychological exchange process, with tasks being carried out as an exchange to achieve a psychic freedom from the dead person. He saw that bereavement increased the outward appearance of affection for the deceased but argued that inwardly there was a corresponding increase in hostility. This was seen as being dormant in the unconscious, but affecting the bereaved with mood swings, depression and a surfacing of emotions. The goal therefore was to detach the bereaved from the deceased thus enabling the bereaved to become a separate being and to come to terms with conflict and ambivalence over the loss of the relationship.

After normal grief, in Freud's theory, there is hardly any change within the bereaved. Although some have taken this to mean that bereavement could be viewed rather like an illness with a possible cure, Freud's point was rather that the human mind has the ability to cope naturally with the loss. Completing the process of the grief work has no time limits but is achieved when freedom, separation and coping with ambivalence has occurred. If a bereaved parent seems to remain in grief, Sanders (1999) suggests that Freud would have concluded that the parent had simply refused to release their attachment.

The problem with this account is that bereaved parents seem to find themselves more entwined with the deceased than before the loss. Parents find themselves thinking about the deceased child more than when the child was alive. The idea of separating fully from the child is a desire that most parents simply do not have. Freud (1961) himself showed signs of struggling to find release from his grief at the loss of his daughter and grandson.

"Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish" (p.239).

Although Freud never modified his writing, it seems that he did grasp a deeper understanding of the loss of a child through his own experience.

Jung's (1963) view of bereavement was of a 'transcendent function.' His view differed from Freud's because he saw spirits of the dead as a psychic fact, real presences, illusions and fantasies which needed to be seen as authentic realities. Jung acknowledged that there was a lack of concrete fact about people's experiences of the psyche in loss, but argued that since the subconscious was not restricted to space and time it was a better resource of information than the conscious mind. He concluded

that this remnant psyche would endure as a conscious personality. Although how this affected the bereaved is unclear (Jung 1963).

LINDEMANN'S IDENTIFICATION OF DIFFERENT AREAS OF GRIEF

Lindemann (1944) took the concept of grief further by distinguishing between normal and pathological grief. From his research of 101 survivors who lost a relative through a sudden, unexpected disaster, illness or in the armed services, he identified grief symptomatology. His work formed the cornerstone in understanding normal grief response. He was the first person to describe 'anticipatory grief.' This occurred in people who, when faced by a probable bereavement, pre-empt the situation and undertake their grief work before the death occurs. Lindemann identified six areas of symptomatology that bereaved people encountered.

1 Somatic Distress.

Lindemann spoke of acute grief as waves of somatic distress. Today we might talk about these feelings as a form of 'panic attack.' These feelings of trepidation and anxiety are common and they can produce disturbing physical symptoms which include the following:

- heart palpitations

- loss of appetite

- ringing in the ears

- digestive problems

nausea

dizziness

nightmares

constriction in the throat

muscular pain

impeded concentration

poor memory

damp hands

dry mouth

insomnia

It is evident that any part of the body can be affected by the stress of anxiety. As people grieve they are caught unaware by sensations they never would have expected to experience.

“No one ever told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing”

(Lewis,1961,p7).

2 Preoccupation with The Image of The Deceased.

At first the bereaved may not believe that the person is dead. This disbelief enables the bereaved to begin to endure the loss. Even when accepting the fact of the loss it is

common for the bereaved to sense the invisible presence of the deceased. This comes in the form of perhaps hearing the noises a son would have made coming in late at night or moving around in the kitchen. Some people sense the touch of their loved one or smell the scent of the deceased perfume in the bathroom. These kind of experiences are similar to dreams. In dreams the subconscious allows things to happen which the person may fervently wish would actually occur.

3 Guilt.

This is an emotion that seems particularly common in all types of losses. People can generate many reasons to make themselves feel guilty. A new reason for guilt can be adopted on a daily basis, and each new guilt can seem as valid as the one which preceded it. Death causes a change in people's circumstances. This change can often be a positive one as well as negative. This too can create guilt. Lindemann (1944) found that those who had survived the war experienced survivor's guilt. This is based upon the belief that one death has somehow been exchanged for another, that one person was allowed to live at the cost of another's life.

4 Hostile Reactions

Death seems to always be an error of the greatest magnitude. People's perceptions of life are often radically altered when they experience loss, which in turn produces hostile reactions. Expressions of anger, aggression and hostility have long been linked to death. The early American Indians talked about the evil spirits and shot arrows into

the air to drive the spirits away (Kubler-Ross,1970). Today we shoot arrows but they are more personal and allegorical. They may take the form of fists or words, letters or lawsuits. The direction this hostility takes varies in the individual. It may be directed towards God or the unfairness of the world. It is often directed to other people but can also include anger towards oneself or the deceased.

5 Inability to Initiate and Maintain Organised Patterns of Activity.

Since the bereaved are preoccupied with their loss, this inevitably leads to a sense of disorganisation. Concentration becomes difficult which makes the bereaved appear to be absent-minded. For some people the experience of low self-esteem, depression and generally poor physical health adds to this confused state.

6 Delaying Grief Work

Lindemann recognised an acute state that was characterised by a rapid onset, serious conditions, and treatable symptoms. When grief appears to endure, Lindemann would see this as a bereaved person attempting to subvert and avoid carrying out the grief work necessary. He believed that, with appropriate intervention, any distorted grief could be transformed into normal grief with a clear resolution. His aim was to emancipate the bereaved from the bond which held them to the deceased and therefore allow them to readjust to a new environment and form new relationships. Lindemann thought it possible to predict the type and severity of grief from

information about the grieving person prior to loss. He also stated that personal traits and environmental influences could effect the condition of the bereaved.

Lindemann developed the idea of working through one's grief. This involved accepting the pain of the loss, reviewing past events, and acknowledging that there will be changes in one's emotional reaction. With the help of a professional carer, Lindemann believed that after a few sessions the grief reaction could be managed.

Lindemann's work laid down a good foundation of understanding of grief from a general perspective. However he failed to recognise the unique nature of grief along with its own particular conditions. His context was one of a war time or post war environment which did not highlight the age of the deceased, whether it was sudden or anticipatory, and did not draw attention to the long term influence loss had upon individuals.

"Lindemann's work can be criticised on the grounds that he gave no figures to indicate the frequency of the various atypical forms of grief which he described or the effectiveness of his method of preventive intervention" (Parkes and Weiss, 1983, p.13).

Nevertheless Lindemann's work set the backcloth for much of the grief analysis that has followed.

BOWLBY'S UNDERSTANDING OF SEPARATION AND LOSS

Another major contributor to the concept of grief was Bowlby (Bowlby, 1969, 1973, 1980). Bowlby's framework for the understanding of separation and loss was closely linked to his theory of attachment. More will be said of this later, but briefly Bowlby explained that humans have an instinctive need to form strong attachments to others. Separation through death or other causes, elicits a variety of behaviours. These might include clinging, crying, anger outbursts, or protest. This behaviour indicates that an attachment bond exists. When relating the concept of attachment to bereavement, Bowlby identifies an initial phase of yearning for the lost person and a desire to re-establish ties with the lost object. He described the overall grief experience as progressing through four stages:

1 Shock and Numbness

This phase involves an inability to truly understand the loss and is reflected in such statements as 'I can't believe it,' 'This isn't happening to me', 'I am dreaming' and feelings of being stunned, interrupted by outbursts of emotion or feelings of panic and distress. Difficulty in making decisions occurs, and normal functioning is impeded. This phase predominates during the first two weeks after the loss. My observations on bereaved parents suggest that, in this stage, it is common for them to feel out of control or in a dream like, unreal state.

2 Yearning

For Bowlby, the feelings expressed during this phase are usually anger, guilt, ambiguity about life, and a profound sense of sadness. There is a yearning for what could have been and a searching for an answer. Here the bereaved desires to retrieve the lost person. The person may be preoccupied with the deceased e.g. seeing a stranger in the street looking like the deceased may trigger thoughts about the lost person. Memories can fill the central focus of the person's thought pattern. This phase is present at the time of loss and peaks sometime between 2 weeks and 4 months after the loss. I have found that parents often experience aching arms, hearing the sound of the baby or child crying, or having disturbing dreams or insomnia. They may be preoccupied with thoughts of anger, guilt, and self-blame.

3 Disorganisation

Bowlby found that this phase is marked by depression, apathy, and despair. This occurs when the mourner turns from testing what is real to an awareness of the reality. This phase peaks at 4 to 6 months and slowly subsides over a year. In my experience, the loss of children lays open parents' feelings that they will never get over the loss or that they are losing their mind; they may even become physically ill.

4 Reorganisation

For Bowlby, this is a time when the bereaved begin to redefine themselves and the situation. Acquiring new roles and skills, the person may begin to formulate new

attachments. Here the mourner is better able to function at home and work with an increase in self-confidence. The mourner has the ability to cope with the new challenges and has placed the loss in perspective. This phase begins to peak sometime after the first year and slowly subsides as parents begin to move on with their lives. Parents usually express that they will never forget their baby or child, but have resumed their life with a new norm. If parents were unable to move forward, here this approach would perhaps focus upon the continuous separation anxiety as a factor to the ongoing grief symptoms (Sanders 1999).

Bowlby mainly reflected upon reports of grief counsellors such as Parkes (1972) which he used to back up his theory of attachment. In time, other grief workers formulated their own stages of grief in a similar progression. Kubler-Ross (1969), related responses of people anticipating their own imminent deaths to five stages. She described these stages as denial, anger, bargaining, depression, and acceptance, however such models do not give enough account for the high degree of individual differences that occur in grief work and rumination (Payne, Horn, and Relf, 1999).

COLIN MURRAY PARKES UNDERSTANDING OF GRIEF

Colin Murray Parkes in his book, *Bereavement - Studies of Grief in Adult Life* (1972) helped to recognise that one of the difficulties of describing grief by descriptive disease categories was the fact that grief was a process rather than a state. Parkes described grief rather as a succession of clinical pictures which blend together

as they replace each other. Parkes recognised the distinctiveness of a bereavement taking place at a specific time and place in a person's life. This may involve stigma or changes in attitude within society when a person dies. Gorer (1965) had similarly pointed this out when he highlighted how people would pity widows and often avoided them.

A further complexity described by Parkes was the idea of deprivation within the loss. This focused upon the gaps that were left by the absence of the deceased. Parkes saw these as the psychological equivalents of food and drink. He saw this as relating to Bowlby's evolutionary theory of attachment with its focus on security. From this Parkes saw how the loss of a close attachment would lead to subjective feelings of insecurity and danger. When you then observe the potential loss of comfort, money, sex and other factors relating to a loved object, it becomes clear that deprivation is also an important consequence of the loss of a close attachment. One of Parkes' main contributions to thanatological studies was to identify what could be termed 'normal grief' as compared to grief with complications. His 'London study' and the 'Bethlem study' helped to identify typical and atypical behaviour in loss as well as to draw attention to the biological nature of grief.

Parkes gave a good series of snapshots of grief.

1 Alarm

Using his biological perspective, Parkes outlined the beginning of grief with the reactions closely linked to the stress reactions of alarm. These result in the physical

symptoms of loss of appetite, difficulty of sleeping, headaches, and general aches and pains. Further stress components consist of pangs of grief with a desire to search for that which is now lost.

Parkes drew on Darwin's study of how humans and animals express their emotions with clear visual expressions like crying and weeping. While Bowlby emphasised the importance of crying and anger protest within the grieving process, Parkes considered that the impulse to find the lost object was of more importance. There is no real conflict here as Bowlby was simply emphasising the fact that the immediate goal of attachment behaviour was to re-establish proximity.

2 Searching

Parkes gives good examples of the searching nature within the bereaved, particularly with parents bereaved of children. This behaviour has one clear aim in seeking to find the lost person and is demonstrated by alarm, restlessness, preoccupation with the loss and the neglecting of oneself to immerse one's attention into the environment which the lost person was associated with. Parkes drew attention to the Aberfan disaster in Wales where 116 children died when a water-laden coal tip slid into a school in 1966. Here he perceived how parents constantly visited the grave and showed no desire to move away from the area of the disaster even when new homes were offered to them. Part of this search for what is lost may even result in suicidal desires as expressed by many of the widows in Parkes' London study. He quotes an example of a twelve year old girl who had been admitted to hospital because of a serious weight loss post the

loss of her mother. Her father had expressed worry that she would become like her mother, to which the girl reacted by saying that that was what she wanted i.e. death was seen as a possible means of successfully completing her search for her mother. Parkes perceived that this searching which includes suicidal thoughts was an attempt to achieve reunion with the dead. It also can be seen as a way of simply ending the present alienation and misery that the bereaved is encountering.

3 Mitigation

Parkes found that the bereaved had times of mitigating the loss with moments in which they may think they have found the lost one. This may come in dream form or perhaps thinking they have seen the deceased in a crowd or on a bus. This sense of losing and finding may occur almost simultaneously as the bereaved's mind attempts to make sense of the situation. Alternatively the bereaved might mitigate the loss by avoiding anything which might remind them of that which is lost. As the bereaved seek to hold on to the memories of the deceased, it is as if the intensity of this desire clouds their ability to see the person completely. Rather like focusing upon only a segment of a jigsaw piece instead of the complete scene. It is only as the intensity of the grief eases that the bereaved begin to see the lost person with a greater sense of clarity.

4 Identity

Parkes was able to see the dilemma of the bereaved as a problem of major change in identity. He later went on to describe this as part of a psychosocial transition. Here, the many assumptions we make in life which allow us to function are suddenly shattered. Parkes (1993) talks about how we develop a defence mechanism. This allows us to take stock until we are able to repair our assumptions of life and gives us confidence in building afresh. This has been described by others as ‘grief work’ (Freud, 1917), and involves preoccupation with the deceased, painful repetitious recollection of the loss experience (worry-work) and attempting to make sense of what has happened.

5 Anger & Guilt

Parkes is helpful in his discussion of the reaction of anger and guilt which is often expressed in the form of irritability within the bereaved. This behaviour can result from a sense of danger that the bereaved feels from the threat of the loss of the attached figure, which the bereaved had felt was recoverable. This sense of danger leads to reactions very similar to those Bowlby observed when children were separated from their preferred figure. One emotional response is identified as ‘blame,’ which is often directed at those caring for the bereaved such as doctors, funeral directors and clergy.

5 Gaining a New Identity

Parkes helps us to see that what Freud may well have seen as pathological, is in fact normal reaction to loss. He highlights the fact that a death of a loved person is so traumatic that it cannot be easily shaken off. In Parkes' study of the London widows, the fact that the deaths were untimely, cast doubt upon the 'expectations of normal life.' If the loss of a husband in his sixties created such insecurities within the widow, then how much more so when the death is of a baby or child. Just as the loss of a husband adjusts the position one plays within society, the loss of a child challenges and alters several parameters within the parents' lives.

LONG TERM EFFECTS OF GRIEF

Bowlby and Parkes' recognition that pangs of grief can be re-evoked years later is particularly clear when it comes to parental loss. A parent's understanding of the world with his or her control of family life, and ability to predict and therefore to act appropriately, is fundamentally shaken. This leaves a void as if part of the parent themselves had died, a void that seems unable to be filled by any other person or thing. Anderson (1949) used the term 'chronic grief' as a reaction within the bereaved that endures longer than normally expected. However this raises the question of what we might call normal grief.

Gorer (1965) attempted to distinguish between chronic grief and those who said 'they would never get over it.' He suggested that the latter were fulfilling a mourning duty rather than truly experiencing grief. Parkes rightly recognises that it is difficult to clearly distinguish between these two kinds of experience. Yet in a society that today tends to expect a limited mourning period, one would not therefore suggest that parents continue to mourn purely because of social expectations. There must be other factors taking place that cause parents to exhibit such long term grief responses similar to chronic grief.

THE DEPTH OF BOND IN RELATIONSHIPS

Although in many relationships it can be difficult to quantify the depth of a bond in terms of love, one might expect a parent-child bond to be a purer example of a love-based attachment. Bowlby talked of a love relationship which can tolerate separation because one expects the loved one to return. This is even more pronounced with a parent-child bond as one expects the life of a child to outlast that of the parent. The parent is therefore not expecting any permanent separation in the sense of loss, from the child of whatever age. On top of this one has the fact that the volume of space a child occupies within a parent's affections, especially a mother, is considerable compared to any other relationship. This all adds to the uniqueness of parental loss of a child.

Parkes recognises this as he points out the difference between the size of families today as compared to over a hundred years ago. Parkes questions whether mothers have only a certain amount of potential for attachment and that it is therefore easier to lose a child out of a family of ten (10% of one's children) than it is to lose one child in a family of two (50% of one's children). But is he right when he suggests that the loss of a child in a smaller nuclear family has a greater impact, than in a family with several children where loss might be more expected? There are two factors at work here. The first is that the more children you have, the more likely you will be to experience loss. It does seem that a century ago people were more expectant of the potential of loss. The second factor is whether a parent's affection is a fixed quantity or whether it stretches with the number of children the parent bonds to. Certainly parents do not seem to say that as they have additional children, they love or relate to subsequent children less than the first. There is also the question of whether it is true that the loss of a child, regardless of age, creates similar grief intensity.

PSYCHOSOCIAL TRANSITIONS

Parkes went on to outline a helpful approach to bereavement by seeing it as a psychosocial transition. Transitions are situations in which a person is faced with the need to give up one world view and develop another. Such changes always require the person to discover the discrepancies between the world that is now being faced and the world that, up to now, has been taken for granted.

"The amputee has to learn not to step on a foot that is not there, the nearly blind must learn that it is useless to look towards the source of noise, and in like manner, the bereaved must stop including the dead person in their plans, thoughts, and conversations. This process of learning is inevitably painful and time consuming. Time and again the amputee gets out of bed in the morning only to find himself sprawling on the floor, the blind person repeatedly peers through sightless eyes, and the widow or widower again and again forgets that the dead partner is gone forever" (Parkes & Weiss, 1983.p.71).

Each time the bereaved makes this mistake, a pang of pain is experienced. As time feels out of joint, it is as if there is a rent in the fabric of reality, nothing makes sense any more. Lacking a clear understanding of what has been lost and what assumptions have got to be changed, the person in transition loses confidence in his or her grasp of reality.

Parkes (1993) recognises that we all maintain an internal assumptive world and behave accordingly. Here we use models to interpret our perceptions and guide our behaviours. We walk through doors with confidence because we have learned at the deepest level of our mental processes that doors separate one region of solid footing from another region of solid footing. It is unlikely that we will meet a door that looks like all other doors yet leads out to an elevator shaft or an empty space. Yet this is how it is for the bereaved who constantly keep walking into empty space. The human

being can be very adaptive in our assumptive world if we have time to slowly adjust. However where there is an absence of forewarning, the difficulty faced is compounded. This is particularly true for bereaved parents. The unexpected loss shows that the world can be unpredictable. Those who have experienced one devastation cannot be confident that lightning will not strike twice.

Parkes found that where there was conflict within a marriage, the outcome of grief for the widower or widow was poor. Among forty five widows and widowers whose marriages appeared conflict-laden there were only thirteen (29%) who displayed good outcomes after thirteen months. This is consistent with the difficulties bereaved parents of teenaged children develop after a period of conflict in relating to a teenager prior to the death.

RECONSIDERING PARKES IN THE LIGHT OF FREUD

There are differing approaches to the problem of loss in families as compared to Parkes. Freud, in *Mourning and Melancholia* (1917), proposed that psychiatric depression (melancholia) might be caused by the real or symbolic loss of a person who was ambivalently loved. His idea was that the lost figure has somehow been incorporated within the mourner. The mourner, once having done this, can persecute and punish the lost figure without risk of retaliation by punishing himself or herself. However why should the mourner fear retaliation from someone irrevocably lost? This could only be because the loss is not real within the mourner's unconscious.

There the lost person still exists, accessible to complaints, accusations, and demonstrations of the consequences for the mourner of having been abandoned. Certainly there is evidence that ambivalence does seem to predispose an atypical grief reaction, and grief is frequently associated with high levels of self reproach. The bereaved can also identify with the deceased such as when some bereaved parents go further and take up interests of the deceased child. Parkes (1983) feels this is too much of a glib answer.

"How can one person be said to incorporate and contain another? Are the self-reproaches of bereaved people really more appropriately directed against the dead?....Those to whom we have established attachments may not stop affecting us when we are no longer in touch with them. They may continue to engage us as partners in our interior dialogues, where they may persist as sustaining or as critical figures" (p.106).

Freud was aware of the concept of 'death wishes,' where a person might wish another dead. The survivor might then reproach themselves with continuing grief as a form of restitution. 'Since I did not love enough when he was alive, I will make it up to him now by grieving for him forever.' Although one can not find 'death wish' desires within parents prior to bereavement, parents do continue to feel that they have let their child down by allowing them to die. This 'failure' in parenting may well trigger a desire within parents to make amends by not ceasing to grieve. Parkes in looking at widows prefers to see this as the loss of hope in making a relationship work. There is also the

possibility that personality difficulties result in difficult marriages and problems in child rearing. Building upon Bowlby's work, Parkes recognises that children who, for whatever reason, have not known the consistent presence of a caring and secure parent may be at some special risk of feeling inadequate and insecure as adults in all their close relationships.

WORDEN'S TASKS OF GRIEF RECOVERY

Another approach to the deepening understanding of grief came from Worden (1983). He placed less emphasis on stages and phases of grief that the bereaved venture through, focusing more upon specific tasks that the mourner has to perform. He saw mourning as a necessary bereavement process which could be conceptualised as four important tasks that must be accomplished:

- 1) accept the reality of loss,
- 2) experience the pain of grief,
- 3) adjust to an environment in which the deceased is missing, and
- 4) withdraw emotional energy and reinvest it in another relationship.

Task 1 - Accepting the Reality of Loss

Worden recognised that the bereaved are initially in a state of disbelief. The first task of grieving therefore is to come face to face with the reality that the dead person is dead. Worden sees the search behaviour acknowledged by Bowlby and Parkes

relating directly to this first phase. This phase can contain elements of denial of the loss or attempting to make the loss seem less of an issue than it really might be.

Task 2 - Experiencing The Pain

For Worden, it is necessary for the bereaved to acknowledge and work through the pain of the loss. If this is not dealt with, then he suggests that it may lead to some symptom or other form of aberrant behaviour. Worden recognises that the community may hinder this process in its attempt to protect the bereaved from experiencing the pain. The bereaved themselves attempt to ease the pain by justifying the death, or spiritualising the situation.

Task 3 - To Adjust To The Environment

The bereaved person in Worden's understanding, needs to adjust to life without the deceased. Part of this is the realisation of the differing roles that the deceased played within the bereaved persons life. Worden builds on Bowlby's and Parkes' understanding when he identifies the many roles a deceased person may have played i.e. a widow may discover that she has lost a sexual partner, companion, accountant, gardener, baby minder, audience etc. Worden sees that people must develop their skills of survival to adjust to this vacuum.

TASK 4 - To Withdraw Emotional Energy and Reinvest It Into Another Relationship

The final task for Worden is for the bereaved to be able to reinvest their energy and life in another direction away from the deceased. This can seem like dishonouring the dead and can therefore be a difficult stage for the bereaved person. As a bereavement practitioner, Worden recognises that this is a stage that the bereaved may need most help to accept and work through.

Worden (1983) writes that mourning is finished when these four tasks are finished.

Although some of these areas of development are clearly seen in the bereaved over time, this does not answer why many bereaved people, especially parents, continue to show signs of grief long after these tasks are completed.

Worden suggests that reactions such as chronic grief, delayed grief, exaggerated grief, and masked grief are signs of not completing his four tasks. He suggests that the task of the grief counsellor is to help,

" people facilitate uncomplicated, or normal grief to a healthy completion of the tasks of grieving within a reasonable time frame" (p.35).

He would leave complicated grief to the therapist. But can one simply put all the bereaved parents who lost a child and who struggle to adjust to their loss in these categories? This will be discussed later in this thesis.

Worden does raise the whole question of whether grief is a passive experience in which there is little a bystander can do to aid the process. For Worden, the idea of phases implies that the course the mourner takes cannot be influenced. Tasks on the other hand are more in line with Freud's concept of grief work and implies that the mourner needs to take action and can be influenced by outside action. The role of a counsellor can be important in both facilitating the grief process and helping to prevent uncomplicated grief from becoming complicated. The counsellor certainly has the opportunity to both facilitate grieving and to educate those persons in the bereaved parent's world who might provide support.

It is paradoxical that the need for social support and the failure to provide it may both be aspects of the same phenomenon, the dependence of the individual and the group upon each other. Recognition of the threat to the social self for both the bereaved parent as well as to the would-be supporter is important. If the loss of a child radically shakes the foundations of life for a parent, we must recognise that it also rocks those who are in a position to care. They too are left reflecting upon their own insecurities, feeling that if this can happen to the person next door, it can happen to me too. There is also in our society today a sense of inadequacy in which people feel unable to cope with those who are bereaved. The caring for the bereaved has become increasingly a job for recognised professionals rather than an untrained lay person. This in turn de-skills the person in the street, and makes them feel that they are unable to care for the bereaved in an effective way. You thus end up with a bereaved parent

feeling unsupported by the local community around them, yet feeling inadequate and desiring support. In the age of the professional, there are increasing numbers of people who see themselves as unable to cope with the problems before them.

Altschul (1988) believes that the bereaved must adapt to their loss through the basic psychic mechanisms available.

" Piecemeal process of recall and remembering with effective re-experiencing whereby the individual is gradually able to achieve emotional distance from the disturbing event, gradually integrating the event and re-establish equilibrium in his everyday life" (p.23).

He acknowledges that even in normal development which may generally proceed smoothly, there are critical periods and phases characterised by episodes of disorganisation and reorganisation.

"There is despair, anger and protest in the disorganisation with a subsequent reworking of affects, memories, reality, leading ultimately to a reorganisation of psychic structure and renewed interest of life. With these stages and expression of the intense affects, there is a piecemeal processing of memories with working through the loss sufficient to reinvest in new relationships and life activities. This is an ideal adaptation and end point that is hoped for all bereaved individuals. However it is not universally reached" (p.24).

The fact that this end point is not universally reached raises questions as to whether something else is taking place within the bereaved which prevents this resolution. It is acknowledged that, as Sullender (1979) puts it,

" a person seeks to disengage oneself from the demanding relationship that existed and to reinvest one's emotional capacity in new and productive directions for the health and welfare of one's future and society" (p.248).

But the degree in which a person achieves this disengagement is questionable. Grief is certainly necessary. Otherwise a person's emotional life remains trapped by the past and one is unable to re-enter, reorganise, reaffirm, and reinvest oneself in the present and future. Grief is caused not by the loss of the loved one but by the value that bereaved has placed upon the relationship. This is why grief crisis is identity crisis. The confusion raises the question in the bereaved of the importance of one's loved one in terms of the survivor's own identity.

Marris (1992) generally sees grief as a process of psychological reintegration impelled by the contradictory desire to recover what has been lost and to escape from painful reminders. He believed that there are two important innate dispositions: the need for attachment and the need to conceptualise. These combine to form habits of feeling, behaviours and perceptions which create structures of meaning enabling adults to predict, interpret and assimilate their environment. When key relationships are broken

or taken away from us, it challenges the meaning in our lives and can lead to a sense of disintegration.

Bereaved people adapt by assimilating reality into existing structures of meaning and trying to avoid what cannot be assimilated. Grief becomes the expression of conflict between the contradictory impulses to preserve all that is valuable, while re-establishing a meaningful pattern of life. Therefore the grief is dealt with not by ceasing to care for the deceased but by abstracting what is fundamentally important in the relationship and rehabilitating it by extracting the essential meaning of the relationship. This is in contrast to the attachment and psychoanalytical theories.

To conclude on Worden, his contribution to the field of bereavement is considerable in terms of helping the individual seek to work practically through their loss. His tasks have proved to be a useful tool for many bereavement counsellors.

To summarise so far, we have over the last century seen a range of views and theories developed, reflecting either upon specific reactions people encountered or explanations to place grief within a specific theoretical framework. We also see that it is extremely difficult to outline the course of what might be called a ‘normal grief reaction.’ This is due to the multidimensional nature of an individual’s grief experience. Yet there is no shortage of bereavement theories which bear very similar characteristics (Sanders,1999). The most important of these are summarised in table 1.

TABLE 1
GRIEF THEORIES

GRIEF THEORIES	PHASE 1	PHASE 2	PHASE 3	PHASE 4
ENGEL 1964	Shock & disbelief	developing awareness	Restitution & rediscovering	Outcome
BOWLBY 1969, 1973, 1980	Numbing	Yearning & searching	Disorganise	Reorganise
PARKES 1972	Numbing	Searching & pining	Depression	Recovery
WORDEN (TASKS) 1982	Accepting loss	Experiencing pain of loss	Adjusting to new environment	Withdraw emotion & reinvesting
RANDO 1985	Avoidance	Confrontation	Accommodate	
SANDERS 1999	Shock	Awareness of loss	Conservation & withdrawal	Healing & renewal

Overall there is a general trend to portray grief as an experience which takes a person into a state of disorganisation which eventually leads to a new reorganised state.

What is clear is that one needs both an overview of the understanding of the grief experience while at the same time recognising the unique nature of the grief within a particular individual.

REVIEW OF EMPIRICAL WORK ON CHILD LOSS

Having outlined general grief theories, the effects of grief upon parents who are bereaved of children will be examined in more detail. There are particular factors that relate to child loss. These include: the inappropriateness of death; the age of the child; the bond between the parent and child; the reaction of the family and community and religious and cultural influences. Two specific researchers, Rando and Knapp have written extensively on the subject of child loss. What follows is a description of their findings and how they relate to other researchers in this field of study.

RANDO'S UNDERSTANDING OF CHILD LOSS

Therese Rando identifies three general aspects of bereavement. First the avoidance of the reality of the loss. Secondly, the need to confront the loss within the bereaved, and thirdly, the bereaved accommodating the loss within their life. However from her research she identified specific factors relating to the loss of a child (1985).

A Death 'Out of Turn'

Since the basic function of parenthood is to preserve the family and protect the child, there is an implicit expectation that the parent will die before the child. Rando acknowledges therefore the unnaturalness of a child dying before the parent.

Psychologically, the process of grieving for one's child involves not only dealing with loss of the loved child, but with the loss of part of one's self. This is because parental attachment consists of a mixture of objective love and self-love (Furman, Kennell, & Klaus, 1976).

Schwartz (1977) described these assaults on the parental self and sense of immortality:

"With the death of a child in the family the blow is felt narcissistically, and as a threat to the sense of our immortality ... the bereavement for the child is intimately connected with, and related to, the libidinal investments. The child serves as a tie with traditional past, but also, and perhaps more importantly, with the future and with our sense of immortality" (p.196).

Jackson (1977) provided further explanation for the unique difficulties inherent in the loss of a child and why this loss serves as a basic threat to the function of parenthood.

"Physiologically, psychologically and socially, the relationship that exists between parents and their children may well be the most intense that life can generate. Obviously, then vulnerability to loss through death is most acute when one's child dies. Not only is the death of a child inappropriate in the context of living, but its tragic and untimely nature is a basic threat to the function of parenthood - to preserve some dimension of the self, the family and the social group" (p.187).

Parents who lose a child are multiply victimised. They are victimised by the reality of the loss of a child that they love, they are victimised by the loss of the dreams and hopes that they had invested in that child, and they are victimised by the loss of their own self-esteem. Kliman (1977) suggests that this is not unlike the survivors of the concentration camps who could not comprehend why they did not die instead.

Rando (1994) suggests that much of parental identity centres around providing and doing for one's children, a basic function of the parent. This is similar to Parkes understanding of the disruption of psychosocial transitions. Parents who have fulfilled the roles of provider, problem solver, protector and adviser, and who have been accustomed to being self-sufficient and in control, must now confront the interruption of these roles and the severing of the relationship with the child. The death of a child robs parents of their ability to carry out their functional roles, leaving them with an overwhelming sense of failure and attacking their sense of power and ability. This is in contrast to the parents' experience of letting go of their child into adulthood, moving away from home, and starting their own families which does not produce any sense of intense grief. Although this kind of loss is another psychosocial transition, the loss is expected and is tinged with a sense of achievement within the parent of a job well done. There is also a positive factor for the parent who sees their child move into adulthood, the hope of further achievements, job prospects, as well as the potential of grandchildren.

The Age of the Child

Rando suggests that the age of the child who dies has no effect on the parent's experience. Rando does not describe the source of the information on which her conclusions are based but she does quote Schiff (1977) who writes:

"Bereaved parents come in all ages. It does not appear to make a difference whether one's child is three, thirteen or thirty when he or she dies. The emotion in each of us is the same" (p.55).

Rando's view is that the "unnaturalness" is not determined by the age of the child but by the role of this person who dies, "out of turn." The unnaturalness of the event becomes a major stumbling block for the bereaved parent, who cannot comprehend why, and can be offered no solace by being told that it was a predictable or expected event.

Much earlier Gorer (1965) had suggested that the most distressing and longest grief is that of a loss of a grown child. Sanders (1980), in her analysis of 102 newly bereaved individuals using a grief experience inventory, found the highest intensity in parents losing children as compared to a partner or parent. Lindemann (1978) suggested that a more severe grief reaction seems to occur in mothers who have lost a young child but he doesn't develop this further.

Kennell, Slyter, & Klaus (1970) looked at the mourning response of parents to the death of a new-born infant. They interviewed 20 mothers and found a higher degree

of mourning in mothers who were both pleased to be pregnant and also had previously lost a baby. There was also high mourning reaction even where mums had touched the baby but had not talked and discussed much with the father. However Klaus and Kennell's idea of rapid bonding of mothers to infants, within hours of birth has not so far stood up to empirical investigation.

Kennell indicated that a number of investigations suggest that the length and intensity of mourning after a loss is proportionate to the closeness of the relationship prior to death. If this were true, one would expect greater degrees of mourning with parents who lose older children. There clearly needs to be further research directly comparing the degree of mourning of parents who have lost babies as compared to older children.

The Intensity of Grief

Rando (1983) along with Fish (1986) reported a surge in intensity of grief years after loss of a child. However there is considerable divergence of views relating generally to the impact of the loss of a child. Some researchers have described a steady decline in the intensity of the grief response over time (Dyregrov & Matthiesen, 1991; Videka-Sherman & Lieberman, 1985). Lang suggests that this inconsistency between studies is not surprising given that most studies have used cross-sectional designs and have focused on different periods since the loss, ranging from immediately afterwards to 36 years later (Lang, Gottlieb, & Amsel, 1996).

Clayton, Desmarais and Winoker (1968) found that parents of deceased children appear to respond to grief most severely when compared to other bereaved individuals, and that they reported considerably more irritability and self-condemnation. Schwab (1975) and his colleagues found in their study that significantly more parents than spouses, children or siblings were rated as grieving intensely. In 1980, Sanders reported having interviewed 102 bereaved individuals and finding that the death of a child produced the highest intensities of bereavement as well as the widest range of reactions. Parental grief resulted in more somatic reactions and greater depression, anger, guilt and despair than did the mourning of those subjects who had lost either a spouse or a parent. She later recognised that the somatic problems seen among bereaved parents indicated that survivors of the death of a child were encountering a high degree of stress (Sanders,1999).

Clyman (1980) found that 80% of their sample of parents who had experienced the death of a new-born felt that they needed some ongoing intervention because of their perceived inability to resume previous responsibilities. Others found that parents continued to report "nerves on edge" (67%), "preoccupation with thoughts of the child" (73%), and "feelings of anger" (60%), 2 years after their children had died of cancer (Payne, Gott, & Paulson, 1980). This is very much in contrast to studies in the past where parents were reported to cope extremely well after their child's death from a fatal illness (Cooke, 1983).

Loss of Primary Support

Rando rightly highlights that the loss of a child strikes at the heart of a marriage. Hence a bereaved parent loses a primary line of support in their partner who themselves are lost in grief. More will be said of the complexity of a marriage in which a child dies later in this chapter, but here we acknowledge that Rando is cautious to suggest that the loss of a child leads to breakdown in marriages. She does recognise that when a child dies a parent will grieve in a unique way which relates to the personal relationship that the adult had with the child. Thus Rando is not surprised that husband and wife may well grieve differently. Other researchers have supported this view. Peppers and Knapp (1980) found mothers' loss more intense than fathers' and suggested it was due to the strong affectional bond in pregnancy along with the mothering role as a socialiser and nurse with the child. They felt secondly that there was a cultural expectation in which men were victims of the "masculine must be strong" ethic. One must question whether this is really the case for fathers. Certainly the marital relationship is particularly vulnerable after a child dies. Videka-Sherman & Lieberman (1987) found high levels of stress in married couples but found no evidence that the divorce rate of bereaved parents approached the 80% level, a figure reported by Schiff (1977). However both studies are from America, and so there is a need to clarify whether women do suffer more than men in Britain.

Cooke (1983) did find evidence of "Discrepant Coping", where one parent expresses their feelings negatively (anger, grief, guilt), while the other partner did not. This led

to poor communication and one partner being perceived as weak. Cooke found that men in particular expressed themselves as if "something was missing". They had a tendency to deal with the difficulties more personally and felt responsible for managing and controlling the family grief. Opposite to prediction, husbands did not turn to religion more than wives, but felt more a loss of direction and purpose in life. Sherman (1982) studied 64 spouse pairs after their children died from a variety of causes. He found husbands and wives coped differently with grief. Women reported using more coping strategies of all types. Women also reported poorer marriage quality than did their husbands. Even families with previous strong and stable relationships described strain caused by the loss and individual grief reactions. Fathers sometimes took refuge in their work and preferred not to dwell on the loss, while mothers wanted to talk about the child and to express their pain through crying. An unexpressive grieving style results in emotional unavailability to the expressive spouse and therefore adds to the burden of expressive grief (Pearn, 1977). Further evidence for gender differences can be found in the appendix (appendix 2, p320).

Social Reactions to the Death of a Child

For Rando, although she recognises all deaths can cause some social stigmatisation, the loss of a child has specific difficulties. The role of a parent in the community often focuses around the activities of their child. Therefore, when the loss occurs, it can also remove the social habits the parent had of meeting and relating to people outside the home. But this raises the issue of the benefits of having a replacement child.

Surely, with the right attitude, a replacement child can aid the recovery of a parent?

However with parents who are too old to have another child (for example where teenagers are lost) the impossibility or difficulty of having a replacement child suggests that one might expect a weaker recovery to take place.

The community support towards a bereaved family plays a role within the bereavement process. The role of the parent and the parent-child bond, with its attendant responsibilities, conspire to determine society's uniquely strange and callous response to the bereaved parent. Although all bereaved people are somewhat socially stigmatised and may experience altered social relationships after being cast in a bereaved role, parents where children have died appear to experience more social stigma than do others. It is common for bereaved parents to experience feelings of abandonment, helplessness and frustration in their experience with other parents after the death of a child. They often complain that they feel like "social lepers" (Rando, 1985). Frequently they are avoided by other parents or find themselves the object of anger when their pre-morbid levels of activity and humour do not return quickly enough.

Bereaved parents represent the worst fears of other parents and consequently they are subject to intense social ostracism and unrealistic expectations, as other parents attempt to ward off the anxieties generated within themselves. Perhaps the "magical thinking" of childhood, the fear that if one thinks and says something it will come to

pass in reality, or an unrealistic fear of "contagion," is not restricted to the young child. This may account for the avoidance syndrome experienced by a majority of bereaved parents. But it is just as likely to be related to people feeling inadequate at dealing with bereaved people. After all what do you say to a parent who has just lost their only child?

Videka-Sherman looked at 194 parents in loss over a period of time. They found altruistic behaviour by many towards others facing the same crisis (Videka-Sherman, 1987). In *Courage To Grieve*, Judy Tattlebaum (1980) refers to Simontons formula for an effective support system: 25% of your support comes from inner resources (from yourself); 20% from your spouse; 55% from the environment or community (Tattlebaum, 1980). However she does not clarify how she determined such percentages. But if this is correct then it is an important thing to take note of, as most couples seem to expect 100% from each other and this leads to difficulties. Knapp (1986) found in his study of parents in loss that the main problem expressed most often by them was the lack of community support in the aftermath of the death and also during the various stages of care in a terminal illness.

Pardoe suggests four key reasons why people cope with grief less well within today's society:

1. As the result of the work of hospitals, night nurses, care assistants, funeral undertakers etc. people experience less of the actual process of death;

2. Death has become less of an event at home and so is seen more as a job for professionals;
3. Sociologically grief is today not contained within the local tribe group but is experienced more individually hence leading to a feeling of isolation.
4. There is a decline in religious faith of an after life and so people have less options to place their hope and comfort in.

It is a common assumption that people, after a few months of bereavement, ought to be getting over it and back into the normal routine of living. By now friends and relatives have ceased talking about the deceased and indeed often actually steer the conversation away from mentioning the dead child's name. Often it is thought that one is saving the parents from further pain by not referring to their lost loved one. It is not uncommon to hear of how a bereaved mum feels when people cross the street rather than to have to face her and not know what to say. Such neglect during the most acute phase of the bereavement process leaves parents isolated and alienated.

Other Problems with the Loss of a Child

Rando warns of over pathologising parents grief reaction especially for those who fall outside the conventional models of grief. She believes that the complexity of a child loss lies partly in the fact that in the western world parents are protected from the

reality of child death. Rando studied 54 parents 2 months to 3 years following the deaths of their children and found an intensification of grief experience in the third year of bereavement (1991). However she recognises that parents do cope and survive the loss of a child. Since Rando is a major contributor to the research of the loss of children, she will be referred to further throughout this thesis.

KNAPP'S SIX FINDINGS ON CHILD LOSS

Knapp interviewed over 155 families who had experienced the loss of a child. He specifically looked at three different types of loss: long illness, sudden or unexpected death, and death by murder. Despite individual differences within the stories and accounts of the bereaved parents, Knapp found several similarities in the way that families, particularly parents responded to the deaths of their children.

Never Forget

Knapp found within parents a deep need not to forget the deceased child. Parents expressed a fear that they would one day not recall their child. Knapp sees this as complicating normal grief and making this kind of loss distinct from other types of losses. Fears of not recalling the sight of the child, or memorising their voices or even losing a concept of their child's unique smell were expressed. Knapp found that parents had a deep need therefore to talk about the deceased and to go on talking well after the community might think it was healthy.

The Need to Die

From Knapp's interviewing, he found that particularly for parents of older children, a deep desire to take one's own life was seen as a way of legitimising the loss. This for Knapp, expresses something of the incomprehensibility of the loss. There appears to be no hope for the parents, who have a deep desire to be with the deceased. Knapp even found this present in families where there were other surviving siblings. Knapp does acknowledge that this is similar to a 'survivor syndrome' which can be seen in sudden loss situations of all kinds, but he found that this feeling lasted much longer than expected. He does not say how long, but he sees it in two forms: the acute stage at the beginning of loss, and the chronic stage lasting over the first year mark. What keeps these parents from taking their lives seems for Knapp to be to do with not wanting to compound the situation for other loved ones in the family.

Survival guilt may develop not only because one continues to exist after the death of one's child, but because of the feelings that one has let the child down by the failure to carry out the basic roles of parenthood. This is a major reason why the resolution of parental grief is such a difficult task and why bereaved parents face so many more difficulties than other bereaved individuals. However not all the problems bereaved parents face have been identified, and where they have been highlighted there is often only a small number of supporting studies. There is also the question of what happens when a parent has another child and whether this reduces the long term impact of the

loss. Are there differences between losing a young child while the parent is young enough to have another child as compared to a much older parent who loses a teenager or young adult? This requires further study.

A Religious Experience

Knapp found that parents often needed to make sense of their loss by finding spiritual, religious answers. This was seen as a way of justifying the loss. Knapp found that about 70% of parents turned to religious faith for answers and comfort. However this process of searching was prolonged when it came to sudden loss and murder situations. In about 30% of cases this led to a real revival of interest in religion. In other cases it took the form of a growing of belief in some kind of reunification with the deceased. This is just a tip of a much larger issue of the effects of different cultures upon grief. Valeriote and Fine (1987) acknowledge that differing ways of expressing grief exist in differing cultures, religions and customs. Since there is a variety of cultural variations relating to death, does this mean that one cannot look for similarities or trends especially when applying it to the loss of children?

Appropriate grief behaviour will be expected according to the cultural setting. In the west, we know that for many parents an overwhelming and chronic effect can be endured for years. A lifelong quest as McClowry, Davies, May, Lulenkamp, and Matinson (1987) put it, to search for the answer 'why'. Given the arguments for the

view that there are significant cultural influences on mourning and grieving, could it be that the pronounced long-lasting grief for a child is a product of western industrialised society? Better health care, lower child mortality, a lower birth rate, and a more individualistic style of community could all influence the effect of grief upon a parent.

In Western societies, parents are expected to grieve in private and to get back to work after a relatively short period. In other cultures however the culturally sanctioned grief reaction may vary widely. Young (in Parkes et al, 1997) cites the case of an Egyptian mother who remained withdrawn, mute and inactive seven years after the death of her child and that this was classed as normal within the mother's cultural setting. In contrast, a Balinese mother may remain calm and cheerful after the death of her child for in her culture any emotional upset is believed to make one vulnerable to illness and to malevolent sorcery (Parkes et al, 1997). Scheper-Hughes (1992) found that in the shantytowns of Brazil mothers showed no sign of grief with babies that they did not expect to survive. More will be said for the reasons for this later. The death of a male child who perpetuates the family name in future generations may be seen as more traumatic in some cultures as compared to others where the male dominance is less observed.

Particular types of death such as suicide and homicide are more likely to cause a shameful reaction within many differing cultures. Anthropologists have observed,

according to Young, that in the history of mankind, infant death provides only abbreviated rites, and grief is often kept to a minimum. This is probably due to the high rates of infant mortality which was expected and still is in many societies today. The nature of the rite differs between societies, but it often varies from rites for an adult death.

"Yoruba of Nigeria dispose of the dead baby by throwing it into the bush. This apparently 'cruel' custom makes sense within this particular culture which asserts that if buried, a dead baby would be considered as deeply offending the earth shrines which bring fertility and ward off death. In contrast, Hindu infants and young children are usually buried rather than cremated since they are expected to return to earthly life and enjoy a fuller experience of it" (Parkes et al,1997 p.194).

Regardless of the cultural setting and its undoubtable influence upon the effect of bereavement, the question of the long term impact upon a parent, especially a mother, needs to be examined. Does the culture exaggerate or suppress what is going on in a parents' grief process? The fact that a community outwardly suggests to the bereaved that they should behave in a certain way, does not prevent the parent from still grappling with his or her loss.

As Young and Papadatou (1997) put it,

"Whichever perspective one takes; evolutionary, social, psychological, or biological, the bond between parent and child is usually considered to be the most significant, powerful and enduring of any human relationship. When either a parent or child dies, not only is the survivor's grief likely to be severe but the loss presents a unique challenge to their future well being and development" (p.191).

While some aspects of the parent-child relationship may be preprogrammed from conception, each unfolds and develops within a specific family, social and cultural setting. It must be recognised that each culture attaches an unique significance to the death of a child. The issue of where children come from before birth and where they go to after death will vary. Also the child's gender, age, family position and how the child dies will alter how a given community reacts to the loss, and in turn, this will vary between cultures.

A Change of Values

Knapp found that in addition to a change of religious perspective, parents changed their value perspectives of life. This was not instantaneous but developed over a period of time. There seemed to be a change from what Knapp calls worldly affairs of goals and achievements to cultivating family affairs and relationships.

Despite the levels of distress reported by bereaved parents on standard measures of mental health and marriage quality, many parents describe positive aspects of "surviving the loss" (Videka-Sherman, 1982). Futterman and Hoffman (1973) found that 48% of parents reported that their grief experience resulted in some positive changes that can be described as personal growth. They found changes in parent's values, including becoming less materialistic and increasingly valuing interpersonal relationships as opposed to careers or personal goals. There was also recognition of a former unrealised potential to act as adoptive parents. People expressed their surprise at their inner strength to survive devastation, leaving them with a sense of euphoria. They found an increasing capacity for empathy and intimacy and a tendency to become more 'present orientated', that is to savour the present. However care needs to be taken when one is talking about personal growth in the light of the loss of a child as it can appear on the surface that the experience of loss is therefore not so great.

More Tolerance

Another common factor that Knapp found was that parents become more tolerant with others and more willing to listen to people with problems. In a sense they become more aware of other people with needs of life like themselves. Knapp was unclear whether this applied only to certain social economic groups or whether it was across all cultural groups.

This awareness in turn causes parents to turn inward to their own resources which Knapp (1986) suggests only intensifies the grief response and lengthens it beyond normal limits. Those most involved in the organisation "The Compassionate Friends" were seen to be the most preoccupied with loss and most likely to use altruistic coping strategies. From Knapp's findings, it is necessary to ask the question whether a self-help group like Compassionate Friends helps families initially but raises and maintains preoccupation with a child long into the bereavement process.

In 1984-5, Klass investigated the Compassionate Friends and found it to be an effective intervention in the severe bereavement after the death of a child. The research method was participant observation. Three decisions formed the framework of description. The decision to attend the group, the decision to affiliate, and the decision to transform oneself into a helper within the group. Affiliation seemed to have a affirming dimension that entailed a unity with those whose lives have also been shattered, an appropriate object on which to attach the energy formerly given to the child, and a sense of family in a supportive community. The decision to become a helper is key to the process, for it is the concept that helping others is the best way to help the self. This allows the parent to reinvestment their energy from receiving help to now giving out support. But one has to question this type of role. How easy is it for the parent to eventually move on and leave the group altogether without feeling that you are letting the group and the deceased down?

This kind of interpretation comes from Klass's psychoanalytical background. As one reflects upon ways in which the community cares and fails to care for those bereaved of a child, it is important to note that the grief process extends beyond the immediate family unit to grandparents, aunts and uncles etc. Ponzetti (1991) called grandparents the forgotten grievers, he identified that grandparents suffer a threefold grief - grief for the grandchild, grief for the son or daughter and grief for oneself. Grandparents show more denial and disbelief than parents. Ponzetti interviewed 45 grandparents in which 78% felt the need to talk, while 64% felt some physical symptoms as a result of the loss. If this is true it raises a further issue of whether siblings might feel the same way.

Shadow Grief

Knapp's last finding, which is central to this thesis, is that of the concept of shadow grief. Much more will be said of this later, however Knapp simply outlined this shadow grief as an emotional residue found within the parents(1980). Knapp found parents, even up to twenty years after loss, to be exhibiting persisting emotions, feelings, and thoughts surrounding the loss. Knapp felt that this was a form of chronic grief which, although not overt, nevertheless was present in parents. On the surface most people would assume that the grief work had been dealt with. Knapp sees this more as a kind of dullness, a dull ache always in the background of the parents' life. This was accompanied by a sense of sadness and a mild state of anxiety, and the parent cannot recall the past without a degree of emotional involvement. Knapp

suggests that the difference between normal grief and shadow grief can be compared to pneumonia and a common cold. Shadow Grief will be discussed in further detail in the next chapter.

Knapp's findings are extremely helpful for those who care for bereaved parents in that it provides a fuller understanding of the long term experience that these parents encounter.

SUMMARY

In the light of current research into grief, the question is raised as to whether grief is universal and constant throughout history or whether there have been significant social changes to cause people to grieve in a way that is appropriate for the culture at that time.

Listening to grieving parents, it is clear there is no quick fix in the process of grief over time. In recent years there have been various understandings of the process of grief which has led to the view that people grieve in a particular prescribed way. Here the bereaved return to a 'normal state' releasing their attachment to reinvest in other relationships. However there seems to be evidence that parents find it particularly difficult to disengage from their deceased children.

The work of Lindemann, Bowlby and Parkes all contribute to the general framework of our understanding of the psychological affects of loss. Whether it be in the form of

understanding loss of attachment, phases or tasks the bereaved experience. But when it comes to the loss of a child there seems to be particular factors.

1) The Inappropriateness of Death

This leaves the parent ill prepared for the loss, shattering hopes and expectations within the family as well as in the community. Accepting the reality of the loss is therefore difficult for the parents.

2) The Attachment of a Child to Parent leads to a particularly Deep Love

Bond in the Parent

It becomes difficult for a parent to adjust to the loss of a child when signs of the bond is still evident in the parent's life. This ongoing bond may mean that experiencing the pain of the loss is extended.

3) The Identity of the Parent's Role in Society after Loss

All loss impinges upon a person's identity, however the loss of a child causes considerable adjustment in the role that a parent plays in the community.

4) The Depth of the Psychosocial Transitions

The loss of a child is a major psychosocial transitions for a parent. This reflects itself not only in the depth of pain experienced by the parent but also in the difficulty of withdrawing emotional energy invested in the relationship by the parent.

5) Discrepancy as Fathers and Mothers React to Loss

The fact that parents' grieve individually within a marriage can result in less support from a partner and greater friction within the relationships of a family. The support structure that an individual might have expected from a loss is shaken by the pain each individual feels within the family and their difficulty in offering support.

6) The Dilemma of Caring for Siblings

The parent's desire to search for that which is lost can cause tension when it comes to caring for other siblings. Grappling with mixed desires of wanting to be with the deceased while also caring for the living is a cause for concern for parents. There is also the tension between wanting to over protect the remaining sibling while at the same time wanting to please them.

7) The Complex Reaction of Communities Leading to Parents Experiencing Isolation and Alienation.

Adjusting to the environment and being willing to reinvest energy into the community is hampered in the parents because the communities themselves find it hard to handle such losses and are ill at ease in how to react.

Researchers such as Rando and Knapp have helped in the understanding of some of the unique factors relating to bereaved parents. However there is still the need for further research. In the next chapter our understanding of the parent bereaved of a child will be more finely tuned as we look at the concept of Shadow Grief.

CHAPTER 3

SHADOW GRIEF AND ABNORMAL GRIEF REACTIONS

This chapter will discuss what shadow grief looks like and will then compare shadow grief with other abnormal grief patterns.

Shadow grief is the emotional reaction that can be seen in bereaved parents years after loss. It is a unique aspect of the long-term response to infant and child death in our society. Knapp described this as an emotion residue in the form of chronic grief, a burden to parents for the rest of their lives. Whether shadow grief is in fact chronic grief is debatable. This will be discussed later in this chapter. Knapp however did contribute to this field of study by revealing some of the characteristics of child loss. He rightly identifies that this shadow grief is not manifested overtly or is too debilitating. On the surface it looks as if grief work has been accomplished, yet parents still in certain circumstances show signs of grief. Knapp recognises that parents may not fully respond to outer stimulation and their normal activity may be moderately inhibited. Under circumstances and occasion, feelings can come to the surface. There is a general feeling of sadness and mild anxiety.

Knapp's contribution requires further interpretation and clarification. When a child dies, the process of grief for parents appears to be no different from any other close

intimate loss bar the fact that the depth of shock of the family and community is high. One needs to recognise that the support and the way a bereaved person handles their loss will clearly affect long-term outcomes (appendix 3). However for parents to be still exhibiting signs of grief after ten years reveals the depth of impact the loss of a child has upon a parent. Bowlby (1966) identified the parent- child bond as a strong one. The remnant of such powerful feelings seems to encumber the parent from resolving their grief. As the years pass the presence of grief is not one of a dominating existence but rather one of a subtle presence.

From the recognised stages of grief, it would appear that parents have completed their grief work. They themselves express how they have experienced emotions of disbelief, anger and despair. As the months progress parents recognise that they do begin to get on with the necessities of life. A degree of reorganisation begins to show in their lives. Yet years later, any attempt at remembering events still brings an emotional reaction. This reaction seems to be constantly just below the surface. If normal grief might be likened to encountering pneumonia, Shadow Grief seems more like being left with a common cold that drifts on and on with no end. This has due affect upon the parents. A general dissatisfaction of life is expressed by parents as they live with 'grey areas of their lives' unresolved. There seems to be no beginnings or endings but a sense of being trapped in the middle of an event that is going nowhere.

OBSERVING SHADOW GRIEF

What will one see if a person is experiencing Shadow Grief? Living with the job of grief 'unfinished' affects the past, present and future of parental lives.

1 Ruminantion

Daily recall of the deceased is common and this inevitably means that a degree of agony and pain is experienced. We see that this is why emotions are so often near the surface and not just at key significant times. Holding on to possessions and the prominence of photographs providing links with the deceased. On entering a home of a parent bereaved of a child, it is usually self-evident from the photographs that a parent has chosen not to forget the deceased. Such ongoing experiences seems to lead to a decrease in the general health of the bereaved. Along with this is the daily struggle of life with the complex relationships between partners and siblings. There is a desire not to move on with life which is manifested by parents maintaining a willingness to want to retell the 'story.' This is just as present in communities where the ritual is to retell the story many times in the early days of loss (see appendix 8).

Parents encounter an 'empty space' within their lives which, although it can be filled, is evolving and changing. Parents have a picture of the deceased which develops as the contemporaries of the child around them grow into adulthood. This means they are always experiencing new thoughts, questions and pains which tie them to the past. This is seen when contemporary children take exams, leave school, get married, etc.

Parents actively chose to include the deceased when asked 'how many children they have in their family. This means that an explanation is always required from the parents. If they decide to not include the deceased son or daughter then the parents can feel guilty betraying the memory of their child. So as the years pass, the picture of the deceased evolves and develops with the parents. They actually carry the child with them in what is now a modified and altered life style. Even the positive altruistic behaviour that results from the loss proves to be a way of maintaining attached to the deceased.

2 Guilt

There is an ongoing guilt and gnawing sense of responsibility for the child's death. It is unclear whether this guilt makes the bond endure or whether the enduring bond causes guilt to remain.. Part of the guilt is that the parent is living and the child is not. Therefore the parent does all he or she can to keep the child alive at least in their memory and lifestyle. Parents at one level will acknowledge that they were not to blame for the child's death, yet parents need some reason to attribute to the death. The attribution theory suggest that people want to believe that the world is controllable and predictable, and when the world is not and terrible things happen, people need to know the cause. In the end finding someone or oneself to blame is less disturbing than living with uncertainty in life. This leads to parents changing their view about their own death.

3 Suicidal Thoughts

Suicidal thoughts are common in parents. It is a way of both escaping the pain of the loss and expresses a desire to follow the child, even if it means leaving other children behind. For the majority however, no suicide attempt take place. This does not necessarily mean that parents actively choose life but rather that they simply did not choose to die. Sooner or later parents try to actively get on with their grief. This involves accepting that their child is not coming back, finding relief from their pain and becoming accustomed to living in two worlds. The question is whether a parent ever detaches themselves from the child. Do parents ever undo the bonds they have formed with their child? Freud himself found when he lost his daughter and then his grandchild that he had a narcissistic hurt. This was a wound to the innermost part of a person, the most self interested self which was irremediable. Freud described this as a deep narcissistic hurt that was not to be healed (Freud, 1959). This leads to parents lacking enthusiasm in their lives. They do not have deep, sensitive feelings any more, their hearts are just not in life as before. They have a 'so what' attitude to death. The sense of total change in a parents life is like starting again from zero. It is not that the child is always in the parents thoughts, but that the child has altered every thought the parent has in life (Finkbeiner, 1996).

"I see myself now through his eyes...he is an extension of myself.. an incarnation.. . he was the part of me that was going to go on into the future... he was my everything" (p.223).

4 Confusion of Identity

Finkbeiner found in her interviews with bereaved parents that they often made a slip of the tongue when talking about their child by using 'I' or 'Me' instead of him or her or the child's name. The daze experienced at first by parents seemed to be recognised by them as the body's way of coping.

"The pain is actually physical, mostly in your stomach and chest. Your chest feels crushed and you can't seem to catch your breath. I remember feeling pinned like a butterfly, or somehow eviscerated. One woman drew an arc that started at her head and ended up at her knees and said, 'His death was cut out here.' The pain comes in waves- moves in, backs off, then in again" (p.4)

Searching behaviour seems a normal pattern in bereavement of what ever kind. Some suggest that it ceases when the bereaved acknowledge that the deceased person is not coming back, but with the loss of children it seems that this searching continues in a different form. Parents will acknowledge that their child's death is final but will also express a feeling that somehow the child is continuing as before. Looking for the child, thinking you have seen the child seems to continue for years in parents.

Perhaps this is more than just early confusion about the finality of death, or the sense of dislocation in the new, unnatural world. It may be a longing so intense that it creates a mild, temporary hallucination, or at least a vivid reminder.

5 The Loss of Older Children

The loss of older children can equally have a long lasting affect upon parents.

Shanfield, Benjamin and Swain (1988) found that after two years, 90% of accident victims' parents were still grieving in contrast to 70% of the parents who had lost children through cancer. The 'accident' parents also experienced more guilt than the 'cancer' parents. There was a significant increase in the number of health complaints among the 'accident' parents, whereas the 'cancer' parents reported no change in their health. Anticipatory grief seems to be playing its role here in helping the cancer parents to begin to prepare for loss.

Because elderly parents experience physical illnesses and handicaps, parents and adult children often reverse their roles, with children assuming an authoritative position over their parents and the parents becoming dependent on the children. When the adult child dies, the parent feels a great void, even if other children survive. The parent feels robbed of a precious jewel, insecure and anxious about the future.

"Forgetfulness may increase, not necessarily caused by senility, but because the parent is overwhelmed with unexpected problems. Physical symptoms become more pronounced and medical problems more complicated. Interest may diminish - not only interest in people and things, but in eating, caring for oneself, and just living" (Williams, 1988, p.15).

The parent whose adult child has died has suffered other losses. Through the years, other loved ones have died, and family and friends have been lost through separation, divorce, and retirement. The aged parent has also experienced the loss of employment, the loss of youth, and the loss of personal possessions, among other things. Three years after the death of a lady's 60 year old son she felt her grief as acute as when it first occurred.

"She described feeling alienated, isolated, and depressed, and often felt no desire to live, although she did not think of terminating her own life. Since her son's death she had suffered two more heart attacks... When speaking of the time since her son's death, Mrs. X said, 'Don't tell me that time heals wounds. I have heard that so much, and it is not true. It takes more than time to heal the hurts if there was real love' (Williams, 1988, p.17).

She went on to explain how people would change the subject when she tried to express her feelings. Often she would kiss her son's photograph and say, "I love you" as they used to do in life. She used the photograph to communicate with him mentally and found it comforting. She tried to put questions to him as though he were giving her advice. She thought about how he would have responded and found it encouraged her.

6 Relationships

The role of the local community can also play a part in affecting how the bereaved adjust to their loss. Often in society we deal with problems by finding a solution. However when no solution can be found it can cause a rift between the bereaved parent and their friends. Friends often attempt to solve the problem by distraction. People's hesitancy to remind parents of their child is not an idiotic assumption that they have forgotten the child but is instead a more subtle recognition that they may not want to be distracted from your distractions. Magic thinking also takes place within the community. Bereaved parents represent the worst fears of other parents and consequently they are subject to intense social ostracism. Thus people 'shy away' from the parents. The result is a huge gap in many conversations. Perhaps this means people have a reasonable idea of what it must be like to lose a child.

7 A Permanent Condition?

Dennis Klass (1988) acknowledges that parents may well cease to show medical symptoms of grief, but will in fact never 'get over' the loss. He suggests that this state is a permanent condition. This is due to the fact that so many aspects of the parents' lives have changed. Their marriages have changed and their relationships with their children and with other people have also changed. They now feel guilty because as parents they are responsible for their children's lives, and the deaths must mean that they have done something wrong. Some of the guilt is part of a larger attempt to lay blame, to attribute the death to some cause, to make sense of it. Their attempt to

understand this leads to a change of perspective and a change of priorities. Such fundamental sweeping changes are a measure of the depth of the bond between parent and children.

People are hurt so personally and deeply that their focus becomes simply themselves. For a while they stop loving anyone and they neglect others, but because couples also expect nurture and attention from each other they feel neglected themselves. The death of a child is not only the end of a fathers lineage but also of his hopes for the child in the future. The projected future is lost. For siblings there is also the fear of getting close to people for fear of being hurt again by loss. Anger is common not only for the parents' sake but for their child who had been robbed of a future life.

THE HISTORICAL EVIDENCE OF SHADOW GRIEF

The loss of children is in fact not a new development. Before the 1850's, children died in huge numbers as they still do in much of the undeveloped world. In ancient Greece and Rome, 30-40 percent of the children died before they were one year old. In France in the 1640's, 20 percent of the children died before a year. Since deaths of children younger than a year old were not recorded, the rates were probably considerably higher. In England in the 1640's, between 25 and 33 percent of all children died before they were aged fifteen. Two centuries later the rate was between

15 and 25 percent. In America during the 1800's, nearly half of all deaths were children under five. In a present day shantytown in north east Brazil, the average mother has 4.5 living children and 3.5 children who have died, these mothers call those who die, 'angel babies' (Stone, 1979).

The reasons for such rates are mostly obvious: appalling sanitation, inadequate nutrition, ineffective medicine. The result, according to historians, was that parents kept a certain distance from children. The high death rates made it folly to invest too much emotional capital in such ephemeral beings.

If so many parents invested so little in their children, what does this mean about the bond between parents and children? Are we wrong to think that the bond is wide and deep? Is the bond, instead, fundamentally casual, depending only on the probability of the child's living? Much of the historical evidence lies in writings, journals, autobiographies, and letters, however it seems that many parents felt the grief but did not record or express it. Stone suggests that this says less about the bond and more about the cultural rules about expressing emotions. Nevertheless parents did experience the pain of loss.

Fanny Longfellow kept a diary all of her life. In 1844 after the birth of her first child she wrote, "with this day my journal ends, for I now have a living one to keep faithfully." By 1847, Fanny had three children and began her journal again. In 1848,

her eighteen month old daughter died. She describes how she lost all interest in the future and seemed to only enjoy her remaining children from hour to hour. As the mother controlled the life of the baby after birth, now after death of the child it seemed that the baby was now controlling the mother (Stone, 1979).

SIMILARITIES WITH ABNORMAL GRIEF PATTERNS

How does this type of grief differ from other forms of abnormal grief patterns?

Worden (1983) described abnormal grief as when grief goes wrong. This is where the tasks of mourning are not completed as part of a persons grief work. Rando (1992) argues that the bereaved are attempting to do one of two things: to deny, repress, or avoid aspects of the loss, its pain, and the full realisation of its implications for the mourner; or to hold onto, and avoid relinquishing, the lost loved one. However it is difficult to separate definitively an uncomplicated grief reaction from a complicated one. Rando (1993) supports this view by stressing that reactions to loss can only be interpreted within the context of those factors that circumscribe the particular loss for the particular mourner in the particular circumstances in which the loss took place. The demarcation is not typically determined by the presence of a constellation of manifestations entirely different from the normal grief response but rather by the intensity or duration of particular symptoms. Certain factors may generally increase the risk of unresolved grief; these include: mental health problems, relationships involving conflict, lack of social support, and unresolved losses from the past. Rando

adds additional factors such as a sudden or unanticipated death, death after an extremely lengthy illness, the loss of a child, and the perception of preventability.

A variety of terms have been developed to characterise problematic grief. They include inhibited grief, delayed grief, grief with memory, chronic grief, traumatic grief, disenfranchised grief and exaggerated grief. There is also a new view of grief in terms of a continual bond which may have been viewed previously as abnormal but has been suggested by Klass (1996) to be present in most grief reactions. A description of each grief reaction will now be outlined followed by an analysis of it in comparison to shadow grief.

INHIBITED GRIEF

Individuals who have inhibited their grief show a prolonged absence of acknowledged grieving (Bowlby, 1980). These people often pride themselves on their self-control and refuse to allow themselves to feel the emotional pain of the loss. For example, although the normal symptoms do not develop, the grief manifests itself through a variety of physical symptoms such as headaches and chronic indigestion (Cooke, 1996). There are some similarities here with shadow grief. Parents do seem to find themselves in communities where it is not easy to express or talk about their loss. This can lead to a sense of inhibition and certainly visiting the doctor with physical ailments seem common. However if parents are given the opportunity to express their grief they seem to do so willingly. Inhibited grief is usually more associated with the

bereaved person denying the grief rather than the bereaved person simply not having an opportunity to express their grief.

DELAYED GRIEF

Delayed grief, in contrast to inhibited grief, finds direct expression but occurs some time after the death. During the time when people normally grieve and deal with their pain, those with delayed grief have no thoughts or feelings that would indicate a loss has occurred. Subsequently, however, a different loss may trigger a magnified grief reaction that is really tied to an earlier one. This type of grief is clearly different to shadow grief where there seems to be no delay in the grief reaction within the bereaved parent.

DISENFRANCHISED GRIEF

This type of grief bears similarities to inhibited and delayed grief. The term was coined by Doka (1987) to describe situations in which the larger society does not socially sanction or recognise certain bereaved persons' right, role or capacity to grieve. Disenfranchised grief is where the bereaved person's experience cannot be openly acknowledged, publicly recognised, or socially supported. Society for example may not recognise certain relationships as being acceptable e.g. relationships that are homosexual or extramarital in nature. In other situations, persons may assume that a relationship has already been severed and that the death of a given individual would

therefore be regarded as insignificant eg. death of a divorced marital partner. In some circumstances, the community may not even understand that a significant loss has, in fact, taken place. eg. miscarriage, stillbirth, death of a pet. Another contribution to disenfranchisement may be the experience that care workers experience when they meet death and loss on a regular basis but are given little opportunity of acknowledging the loss eg. Doctors, nurses and clergy. This concept recognises that societies have 'grieving rules' that seem to specify who, when, where, how, how long, and for whom people should grieve.

Feelings of shame or confusion may be experienced when the rest of the community fail to acknowledge the experience of grieving. Guilt, shame, anger, embarrassment, loneliness and isolation are common responses. Doka describes this kind of grief as a hidden sorrow. He recognises this grief reaction being present where prenatal death or elective abortions take place. Often relatives and the nearest community are not a part of the experience of the loss and therefore do not relate to how the parents may be feeling. This analysis of grief focuses more upon the social setting and its influences upon the bereaved rather than the emotions that take place when loss occurs. There is no doubt that for bereaved parents, the reaction of relatives and the community influence their encounter with grief and how they deal with this grief over a period of time. However it is doubtful whether parents' long term encounter with grief would be greatly reduced by a different community reaction. In any case the reaction of a community to the loss of a child is more related to the difficulty of knowing how to react and support bereaved parents rather than not expecting parents

to exhibit grief. Where disenfranchised grief may be present in parents is when a community assumes that when a parent gives birth to other children, then the loss of the deceased child should have little affect upon the parent or after several years following the loss, when a community may expect the bereaved parents to be fully recovered from their loss.

CHRONIC GRIEF

Chronic grief is where grief is manifested intensely and lasts well beyond what is regarded as the normal grief period (Cook, 1998). The bereaved continue in such an intense stage of grief that they cannot plan for the future or reorganise their lives.

Aiken (1985) has indicated that one symptom of chronic grief is psychological “mummification” of the deceased. This is the phenomenon whereby the bereaved attempts to leave things just as they were when the deceased was alive.

However if Shadow Grief was simply chronic grief as others have characterised it, then one would not expect parents to continue to evolve in their grief process.

Instead one would see parents in a more fixed rigid state within their grief.

Bereaved parents often distrust their ability to manage without their child. This includes overall anxiety and fear of nervous breakdown. When there is yearning for the deceased, preoccupation with thoughts of the deceased, feelings of helplessness and indecisiveness, these often combine to leave parents emotional drained for years. Parkes describes this as an indicator of chronic grief. The level of dependency also

plays a part in the grief reaction. In dependency, there is usually a relationship between a weak or not-able-to-cope person (a child) with a stronger or more-able-to-cope person (a parent). Dependency involves an interlocking of emotional needs between the two individuals. This is true in parent-child relationships. The parent may well seem often to be the dominant force within the family, but strength can often arise because of the presence of the weaker individual.

It is a reasonable assumption that the child's view of themselves and others travel with them into adulthood and therefore affect other relationships in their lives. Parents are well aware from their own upbringing whether it was a positive or negative experience that a parent's role is one of protection and support.

The fact that death has occurred is now a constant reminder that they have failed in this respect. Parkes (1983) talks about a lady who was widowed summoning her husband's memory thus giving herself a deeply reassuring feeling. This summoning describes the bereaved actively seeking to hold on to the deceased. Many parents echo this, telling how they actively desire to maintain the presence of their child within their life routine. Parkes goes on to observe an inability within some widows of being able to cope alone and he identifies this as a sign of the persons dependency on their spouse during marriage. These he believes are the people who are most likely to resist resolution.

"We regard it as a disorder of attachment, a condition in which the biologically determined ties that link two people together and normally ensure mutual security and effectiveness have become distorted to the point where security and effectiveness are impaired" (p.153).

Parkes and Weiss identify four possible factors. Firstly, there is the person whose fear of unfamiliar situations makes them withdraw. Secondly, there are those who continue to turn the fantasy of a continued relationship with the dead person, in order to maintain an illusion of security. Thirdly, there is the lack of confidence in oneself so the world outside can make the bereaved feel safer in their own world of the past. Finally, there are the occasions when grief is socially sanctioned with gentleness and tolerance such that the bereaved find it tempting to remain in this environment of sympathy and support.

To try to distinguish chronic grief from shadow grief, it is worth looking at each of these points through the eyes of a bereaved parent. Consider first the fear that leads to social withdrawal. Before their loss, bereaved parents will most likely have been surrounded by parents with healthy children, and their social life may have been embedded in a community of parents. After the loss, associating with this social groups only highlights the loss, and so becomes a source of fear. This fear may be heightened by the withdrawal of the community from the parent, who are also struggling to cope with a bereaved parent in their midst.

In regard to the fantasy of the ongoing relationship, it is true that parents tend to maintain a high profile of the deceased within their home environment. Here parents may maintain the child's bedroom exactly as it was before death, or increase the number of pictures in the house of the deceased, or simply place an important possession of the deceased in a prominent position in the house. There is also a sacredness about the deceased, where the deceased's words and attitude can become fixed, never to be challenged. We see this when parents take on the interests of their deceased child. This is also evident when the replacement syndrome takes place in which the next child never lives up to the imagined achievements of the deceased.

Thirdly, when parents have invested so much of themselves in a prodigy, only to have this wiped out, for many in a sudden and unpredictable way; it is understandable that for some, the will to begin again in life has been severely damaged .

In regard to the fourth point, this is probably not typical of bereaved parents as usually the close community becomes tired of caring which leads to an increasing degree of isolation in the bereaved. Even when couples and children can comfort one another, this may perpetuate the situation with no real sign of any initiating change.

Parkes concludes that chronic grief is essentially determined by insecurity. This insecurity is a large factor when it comes to bereaved parents who now see the

vulnerability of life from every angle, especially when it comes to their other remaining children.

The long duration of Shadow Grief gives an understandable impression that it is similar to a form of chronic grief reaction. Rees (1987) describes a female patient who came to him thirty years after the death of her only child. She had a history of attempted suicide, arthritis and muscle pains. She was invariably depressed and never felt well. Her medical folder bulged with reports from various specialists including Psychiatrists. Her son had fallen off his bike while riding on a towpath and drowned in the adjoining canal. The women blamed her husband for the death, retaining a constant bitterness towards him and never forgiving him or herself. They remained married but never talked about their child. Even when the son would have been old enough to leave home and marry. The mother still remained engrossed in the feelings that had become dominant years previously. The pattern had become so permanently fixed that Rees felt that any chance of recovery could not be discounted. This seems to have more the characteristic of chronic grief although it does not rule out the presence of shadow grief.

GRIEF WITH MEMORY

Grief with memory is a common experience when a bereaved person is reminded of their loss. This might manifest itself particularly at anniversaries, Christmas or at special family occasions when people's attention is drawn to the fact that the deceased

is not present. Other occasions might include visits to familiar places or returning to the grave site. It seems clear that Shadow Grief is not just another form of memory with emotion. What differentiates it is that Shadow Grief involves almost daily recall. Indeed this process seems to be a positive as well as negative encounter, involving an active initiative upon the parent. Parents will experience grief with memory particularly at the times of key anniversaries in addition to their daily recall.

Parkes (1983) recognises that emotional acceptance of loss is rarely complete. A flash of memory or a sudden association that subjects them to intense pain is common in all bereavement. However, for parents this seems to be an ongoing process. A parent's desire to maintain some identity with the deceased comes at great mental cost to them, many develop the ability to relate to the outside world while carrying an ongoing burden of the past. What is clear is that the concept of parenthood continues after the death of the child. This is seen also with widows and widowers who function as if still married. Many adults reach the stage where they feel they are no longer married and eventually may find new friends and partners. Parents too, if young enough may have other children, but this in no way acts as a substitute for the loss. There is in a sense a duty to the deceased child to continue mourning, thus holding on to some kind of hope for the future. This may be a covert way of obliging the spirit of the deceased which seems to the parent, to always be near.

The concept of moving towards a new identity can only take place when the deceased so wishes it. This can seem to take place for those bereaved of partners but is more difficult for bereaved parents. The idea of having a new identity separated from their deceased child is a negative desire. The insecure experience of the bereaved is and can be eased by family and friends. For parents bereaved support groups such as Compassionate Friends can be invaluable. This is especially helpful where parents find it hard to find a new role in their community after the death of a child. It is in the light of such difficulties that shadow grief becomes a reasonable response to an unreasonable situation.

TRAUMATIC GRIEF

Jabobs (1999) seems to see traumatic grief as something that endures for over a period of two months or so. He recognises that anniversaries may be difficult but that if they become an overwhelming nemesis, where the distress is severe, prolonged, and persistently disruptive of psychosocial functioning, then this is a clear sign of Traumatic grief. Jabobs differentiates between the works of Bowlby and Parkes in which pathological grief is seen as being rooted in attachment theory as compared to Adler (1943) and Horowitz (1997) who identify pathological grief as having roots in trauma and stress. Jabobs adds to this work by identifying traumatic grief as being initiated by separation anxiety. His criteria for this type of grief is helpful in giving some clear pointers to grief counsellors (table 2).

TABLE 2

JABOBS CRITERIA FOR TRAUMATIC GRIEF

CRITERION A	1. Person has experienced the death of a significant other. 2. The response involves intrusive, distressing preoccupation with the deceased person(e.g. yearning, longing or searching).
CRITERION B	In response to the death, the following symptoms are marked and persistent: 1. frequent efforts to avoid reminders of the deceased (e.g. thoughts, feelings, activities, people, places). 2. Purposelessness or feelings of futility about the future. 3. Subjective sense of numbness, detachment, or absence of emotional responsiveness. 4. Feeling stunned, dazed, or shocked. 5. Difficulty acknowledging the death (e.g. disbelief). 6. Feeling that life is empty or meaningless. 7. Difficulty imagining a fulfilling life without the deceased. 8. Feeling that part of one self has died. 9. Shattered world view (e.g. loss of sense of security, trust or control). 10. Assumes symptoms or harmful behaviour of, or related to, the deceased person. 11. Excessive irritation, bitterness, or anger related to the death.
CRITERION C	The duration of disturbance (Symptoms listed) is at least two months.
CRITERION D	The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

There is some overlap between these criteria and a bereaved parent’s experience of grief. One area that seems to be different is with the parent’s desire to focus in upon the deceased child rather than avoid contact with memories as in criterion B. Criterion D does not fully apply to shadow grief for although parents are affected by their loss, they are still functioning normally in society. What is important with shadow grief is

that many of these symptoms are indeed marked and persistent but in the long run to a far lesser degree.

Jabobs is right in recognising the multidimensional nature of the symptoms. Guilt during illness (Parkes, 1970), survivor guilt (Prigerson, 1995), despair (Prigerson et al, 1995), suicidal ideation or self destructive behaviour, loss of previously sustained beliefs (Wortman & silver, 1989), anger and protest at authorities (Lindeman, 1944; Parkes, 1970) and also social withdrawal (Prigerson et al, 1995) are all factors that are indeed present within the bereaved parents. Prigerson (1997) suggests that when traumatic grief is present then there is also a high risk of factors such as suicidal ideation, heart trouble, high systolic blood pressure, cancer and high risk health behaviour such as excess consumption of food, alcohol and tobacco along with a possibility of panic attacks. Jabobs believes that if traumatic grief is left untreated then there is the likelihood that the grief will become chronic and unremitting (p36).

The question is whether traumatic grief is any more distinct than chronic or disfranchised grief disorders? Jabobs (p.8) cites a lady, only seven months bereaved of a child, requiring traumatic grief counselling. Perhaps the key to this diagnosis is whether the bereaved themselves feel they require psychological counselling. In fact, in the bereaved parents interviewed the first three to four years could be characterised as being similar to chronic grief in intensity. Nonetheless they do find themselves moving forward at a slow pace into new areas of life. This is more like the dual

concept of grief proposed by Stroebe and Schut (1996) where parents can only cope with so much grieving at one time.

Jabobs does help in giving a a useful metaphor for grief as he likens it with an injury with inflammation. Here the natural course of grief is the inflammation. After the loss the bereaved are basically injured. If the grief persists or becomes intense then an abscess may develop i.e. traumatic grief (or I suggest some other grief disorder). In a sense shadow grief becomes the long lasting scar that is still prone to inflammation and soreness.

Janoff-Bulman (1992) draws from his understanding of post traumatic stress disorder to draw attention to how bereavement attacks a person's assumptive world. The assumptive world is where our view of reality allows us to be confident to recognise, plan and act. Janoff-Bulmann draws from Stern's work(1985) on generalised episodes of how a person expects life to proceed. From episodic memories which form an infant's representation of their core self, culture and society help to build the person's internal representations. This leads us to a cognitive conservatism which stands us in good stead most of the time. Our theories serve as guides that enable us to make sense of our world. Changes in this perspective are usually gradual and incremental. However Janoff-Bulmann found that traumatic events had a profound impact upon a person's fundamental assumptions about the world. When one's assumptions are seriously challenged, an intense psychological crisis is induced i.e. a time of trauma.

This can lead to a sense of helplessness, an apprehension that anything can happen. Janoff-Bulman believes that there is some evidence that overwhelming terror may be capable of changing brain chemistry such that survivors are more sensitive to adrenaline surges even decades later. It is also difficult to maintain a belief in a wholly meaningful world in which events make sense and happen in accordance with our accepted social laws. This fear of the randomness of life is particularly difficult for bereaved parents with other surviving children. They face the question of whether to be overprotective of the siblings or, since one cannot control the randomness, to give the surviving children more freedom. The relative plasticity of the child's inner world provides the possibilities for both greater psychological protection from trauma as well as for greater psychological devastation. One must question the impact upon siblings who have experienced the loss of a brother or sister upon their potential ability to parent in the future.

The cognitive strategy to cope with such events is to re-establish cognitive stability and emotional health. Pennebaker (1990) argues that disclosing a traumatic event is associated with better results. Parents who join self-help groups such as Compassionate Friends seem to find this opening process helpful, but a comparison needs to be researched with those who choose to deal with their loss in a more private way. Janoff-Bulman cites parents of children with leukaemia who blame themselves as a way of protection from an intolerable conclusion that no one is responsible and that therefore neither expiation or propitiation can undo a malign event which has come

about impersonally and meaninglessly (Chadoff et al., 1964). Although the bereaved may use adaptive cognitive strategies, Janoff-Bulmann does recognise that for some people they can still be struggling many years later. It needs to be recognised that some people are more capable of re-appraising events in a positive and meaningful way. The choice lies in interpretation and reinterpretation, appraisal and reappraisal, evaluation and re-evaluation. Others clearly play a role in this process, providing a mirror to allow reappraisal to take place. But Janoff-Bulmann rightly points out that this may give rise to both positive and negative effects. For example although self-help groups can be supportive in the initial stages of trauma, there can be a danger if one remains trapped within such a group preventing an individual from moving on in their recovery.

Janoff-Bulman concludes that most trauma victims cope successfully although they do not return to where they began psychologically. Their experience is encoded in their assumptive world. The legacy of this is some degree of disillusionment, tempered with hope, sadder and wiser. This is clearly not the case with most bereavements unless the loss is an enormous psychosocial transition which would include some examples of child loss.

EXAGGERATED GRIEF REACTION

Perhaps Shadow Grief resembles more closely the concept of exaggerated grief reaction. Here there is a conscious excessive and disabling reaction. For example a

person's anxiety levels may become excessively high. Worden (1983) recognises that guilt is usually a factor in such cases. It is true that the guilt levels of parents in all communities observed were high and long lasting. A natural reaction for a parent is to protect their children from harm. This is even evident in older parents with grown up children.

As previously mentioned, suicidal thoughts are common with bereaved parents. This also is seen where grief is exaggerated. However, although parents may still have such thoughts years later, the degree of thinking about suicide does diminish. This is also true of despair and depression. It seems that in Shadow Grief parents will indeed experience and encounter what would be called as chronic and exaggerated grief. However in Shadow Grief this experience is still dynamic and evolving rather than being static in a fixed state.

Here the parent's understanding of the deceased is in a process of change. It is recognised that in all losses, the bereaved think about the deceased. They may imagine the person growing older, moving house with them or being with them on holiday. It is not uncommon for bereaved spouses in their thoughts to ask for permission to remarry from the deceased partner, or to be comparing the new partner with the deceased. However when it comes to the loss of a child, there is just so much of the script of that person's life unwritten. The parent almost continues to write the story in their minds and in how they then choose to live. With any adult loss, it is possible to

see enough of the jigsaw or picture of that person's life to see it as a whole even though it is not complete. Yet with a child there is such a vast open space on the canvas that every day in the parents' lives they are involved in imagining completing the picture. The loss also leaves a blank space in the parent's own understanding of their lives which they struggle to fill with anything else that is meaningful.

Gradually in Shadow Grief these emotions will subside but a residue of each remains. Therefore Shadow Grief must not be confused with abnormal grief patterns. Rather it is a long process which is a normal grief pattern for a bereaved parent.

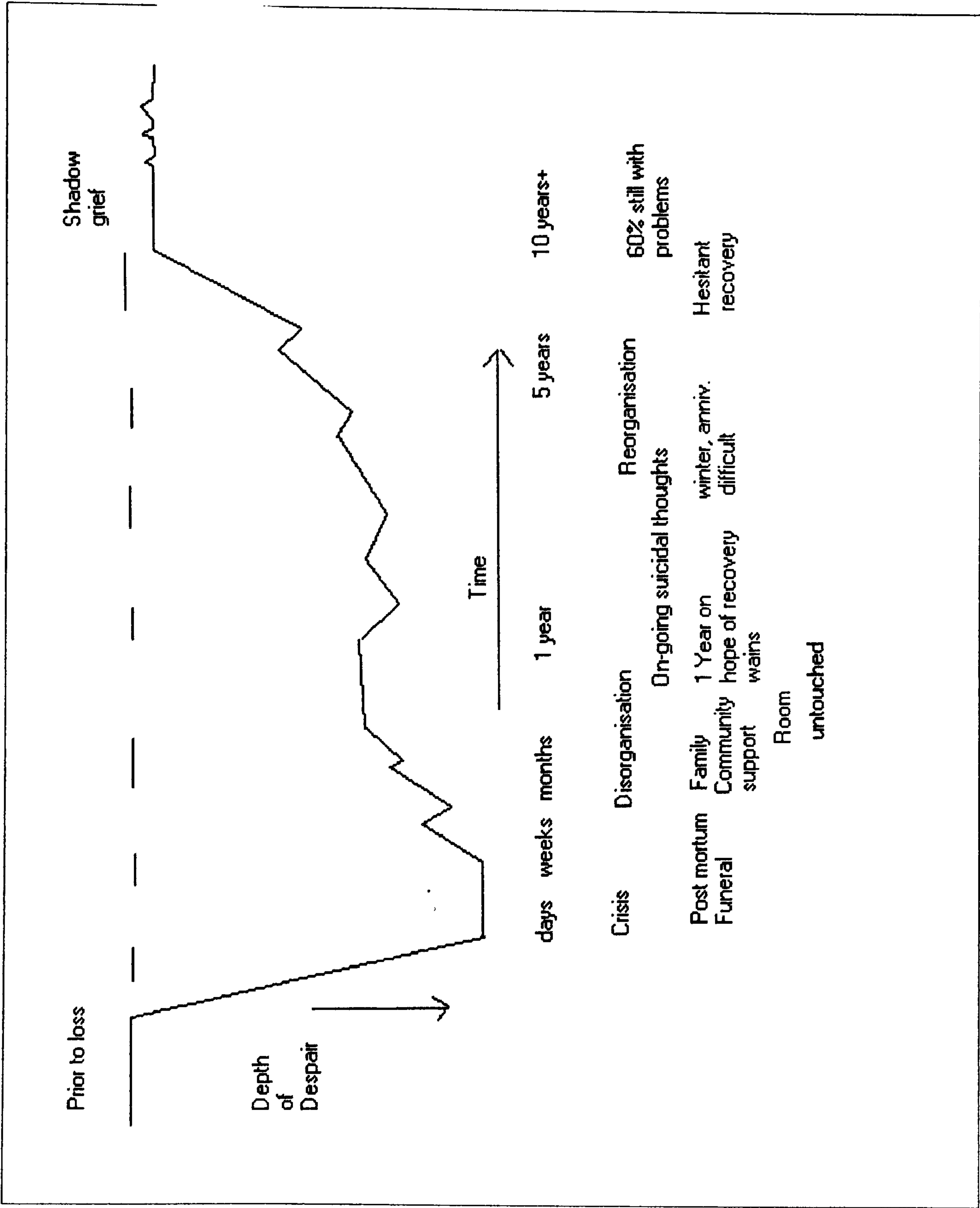
A SUMMARY OF SHADOW GRIEF

The grief experience of bereaved parents can be seen to contain various elements of current grief models. Most of these models have some element of overlap in their description of grief reactions. Each model has been developed to help those caring for the bereaved to understand and grapple with the bereaved person's experience. However when it comes to the loss of a child, each model does not fully explain the reaction found within parents. Parents acknowledge their grief and are recognised by the community as people grieving, yet also show signs of high social isolation, despair and death anxiety. The sense of intensity of grief that this reflects is one of the reasons why parents find that they eventually lose support from the community. It seems that the bereaved are not stuck on a particular emotional reaction but are on a long

bereavement learning curve. This involves a process of change and adaption to the loss, while still not fully recovering from the grief (Figure 1).

FIGURE 1

THE BEREAVEMENT CURVE



Within this curve parents do experience chronic grief reactions within the first few years. Constant visits to the Doctors are common for aches and pains and the thought of suicide is particularly high. Research has determined that bereavement and loss is associated with changes to immune function, especially immuno-suppression (Ironson, Wynings, and Schneiderman, 1997). This correlates with the high levels of stress that bereaved parents manifest (Bartlett, 1998). However eventually parents are left with a smaller degree of stress. This is more related to the daily recall process and the yearly difficulties of dealing with anniversaries, birthdays etc.

There is a degree of overlap with the abnormal grief reactions outlined. They are summarised in table 3. The loss of a child however seems to express a unique experience that needs to be characterised in its own way. Shadow Grief is the nearest expression to that encounter of grief. In the next chapter, the nature of the parent-child bond will be investigated in regards to how it affects shadow grief.

TABLE 3

ABNORMAL GRIEF REACTIONS

INHIBITED GRIEF	Prolonged absence of acknowledgement of grief. physical symptoms eg. headaches.
DELAYED GRIEF	No reaction in early stages of grief. Triggered by other losses or major events.
DISENFRANCHISED GRIEF	Not socially recognised, openly acknowledged or publically supported. affected by societies 'grieving rules.' shame, guilt, embarrassment, loneliness, and isolation common.
CHRONIC GRIEF	Intense and long lasting grief. Affects daily life style and future planning. A fixed state with yearning for the deceased, preoccupation with the loss, helplessness and indecisiveness. A fear leading to withdrawal from community and a fantasy of the deceased. Lack of confidence. Socially sanctioned to remain in grief
GRIEF WITH MEMORY	Reminded of loss by special occasions, places or by possessions of the deceased. Emotion present on recall.
TRAUMATIC GRIEF	Intense period of loss of about two months or over. Distress is severe, prolonged and persistently disruptive. Significant impairment in social and occupational function. Physical symptoms, suicidal ideation. can lead to chronic grief.
EXAGGERATED GRIEF	Conscious excessive and disabling reaction. Anxiety and guilt levels are high. Suicidal thoughts. Despair possibly leading to depression
SHADOW GRIEF	An emotional residue that remains with the bereaved. High levels of despair, guilt and suicidal thoughts. Holding on to possessions and visiting the grave. Daily recall years later. Involving the deceased in decisions for the future. Relationship with the deceased interactive eg. attempting to perceive what the deceased would be like at present time. Significant effect upon current relationships and attitudes of life. Holding onto the pain of loss as identification with the deceased.

CHAPTER 4

THE PARENT-CHILD BOND

This chapter will look at the nature of the parent-child bond to see if this bond can help explain why grieving for a lost child endures longer than grieving for the loss of other kinds of close relationships.

It was Bowlby (1988) who laid the foundations of our current understanding of the relationship that is formed between a child and parent by formulating attachment theory. A key feature of Bowlby's theory is his notion of an internal working model based on cognitive representations of the self, the other and the relationship. He envisaged a developing child building up a set of models of the self and others, based on repeated patterns of interactive experience. These cognitive relationship models are used by the child to predict and relate to the parent. A securely attached child will store an internal working model of a responsive, loving, reliable caregiver, and of a self that is worthy of love and attention. The child will then bring these assumptions to bear on all other relationships. It is on this basis that Bowlby saw internal working models as underlying patterns of secure or insecure attachment.

Internal working models provide the mechanism whereby childhood patterns of attachment are carried through into adult life. Experiences of interacting with new

people are interpreted in the light of this cognitive representation of the first important relationship, and hence influence the nature of cognitive models underlying subsequent relationships, especially close affectionate ones. Bowlby saw marriage or its equivalent as an adult form of attachment when companionship provided a secure base allowing exploration, work and play.

Although relationships are defined in terms of two or more people, they require psychological processes internal to each individual. Thus we talk about the child's bond with the parent and the parent's bond with the child as distinct concepts even though they are both constituents of the same parent-child relationship. The idea of an internal working model denotes one kind of internal process. Each partner in the process will have internal representations, and each will influence the other's representations, but the two sets of representations are still distinct entities.

The core motivation underlying a relationship may also be different for two people in a relationship. Bowlby and Ainsworth suggest that the core motivation for the child is to maintain a feeling of security. Feelings of insecurity initiate attachment behaviour - actions likely to have the effects of bringing about proximity to the parent, which reduces feelings of insecurity. In contrast, the core motivation in a parent is widely described as one of caregiving or nurturance. Ainsworth (1991) suggested that a parent's bond with the child was perhaps the archetypal caregiving relationship.

Ainsworth used this insight to clarify how we think about a variety of different kinds of bonds. She used the term “affectional bond” as a superordinate category to describe a variety of long-enduring bonds in which the partner is important as a unique individual. Here being together produces pleasure while separation causes distress and loss causes grief. She argued that there are various types of affectional bond, including attachment of a child to a parent, and the caregiving relationship of a parent to a child. Other types of affectional bonds might well include close relationships between siblings, between close friends or between partners in a married or similar relationship. Thus Ainsworth saw attachment as one particular kind of affectional bond where security was the core motivation. She was quite clear that because security was not a core motivation in most parent’s bond to a child, such a bond could seldom be characterised as an attachment. Bowlby himself viewed caregiving as complementary to attachment behaviour. Moreover, since the way in which an individual's attachment becomes organised within his personality affects the pattern of affectional bonds he makes during his life, one might expect this background to affect parents’ grief reaction to the loss of a child.

Bowlby did not see any significant difference between the pattern of response to the death of a child as compared to an adult. He only mentions the significance of the role of loneliness which he sees more prevalent in adult loss and less so in parents.

However he does conclude that:

"These observations are of great significance for the theory of affectional bonding. They show that, whatever the different types of affectional bond may have in common, they cannot be regarded as identical. Thus to make progress it will be necessary to study not only the many characteristics that different types of bond have in common but also their differences. In view of the number of types of bond - child to parent, parent to child, spouse to spouse, and sibling to sibling with the many subtypes due to sex differences - this represents a formidable undertaking" (Bowlby, 1988, p.124-125).

Bowlby saw the inner working models as analogous to maps and plans. This is used to simulate and predict the behaviour of others in social interaction, as well as to plan one's own behaviour to achieve relational goals. The internal working model is the key concept for Bowlby in understanding how the nature of the child's bond with the parent carries forward in time to influence subsequent personality and social relationships. Thus the internal working models underlying a person's relationship with a spouse or partner, and with a child, will be influenced by the internal working model underlying the relationship that the person had, as a child with his or her own parents. The bonding process is considered further in appendix 5.

Feeney (1996) recognises that relational goals within a child may initially be simple but become more sophisticated and complex in adulthood. It is these sophisticated

goal directed systems that become disrupted by the death of a child. Loss within an adult will reveal degrees of vulnerability which may still produce signs of the childlike attachment first formed in the early months and years of life. The process of grief work is well recognised as having a primitive link with this original bond formation. However the bond between a parent and its progeny is multifaceted. Just as the child holds multiple representations for the parent, so too does the child's death hold multiple meanings for the parent (Rosenblatt, 1993).

HOW PARENT-CHILD BONDS INFLUENCE GRIEF REACTION

Previous models of grief have been based upon attachment theory and particularly on observations when young children are separated from their mothers. However this does not account for the long term grieving observed in parents when they lose their child. What is it that makes the parent to child bond different from other affectionate bonds that results in this difference? This draws attention to studies of primates, differing types of bonds, social and communal influences and the inner perceptions of parents.

Primate Studies

A review of Klass and Marwit's (1988) research on parental grief may assist us. They suggest that since primates are humans' closest relatives, the nature of the parent-child bond in primates could give us clues towards the mechanism of this bond. Hrdy (1981) draws attention to the fact that primates invest greater time into raising

fewer and higher-quality offspring. Klass and Marwit also draw upon Lawick-Goodall's (1971) study of Chimpanzees which reveal that the parental bond is not just a maternal bond. Klass and Marwit rightly point out that since the maternal bond is more constant and long lasting than the corresponding bond from the child's perspective, then one would expect a different grief reaction in loss. Klass and Marwit also noticed in Lawick-Goodall's work the role of status within the group of monkeys where the survival rate is higher for the offspring of high status females and males. They conclude that this status could be translated into a feeling of worth or competence in humans. They therefore suggest that the security of a person's place in society could be related to the survival of one's children.

Bonding Concepts

Building upon the work of Turner (1970), Klass and Marwit identify four types of bonding that help to clarify differing types of bonds within relationships. These are contractual, sacred, identity and creative bonds. Contractual bonds are those in which people enter on the basis of mutual obligations from both sides of the relationship. These bonds may be abandoned if the interactions are no longer reciprocal. An example of this would be a marriage arrangement. This is in contrast to a sacred bond which are suggested to be bound together by, 'obligations to God,' or to ancestors or to an abstract moral principle. Here these bonds cannot be broken by the lack of interaction because they are not contingent on changes in the behaviour of the two parties concerned. Klass and Marwit suggest this characterises a parent to child bond.

One can see how this is the case for parents but there needs to be a deeper working out of the terms such as ‘obligation to God’ or some other abstract principle. This seems to still leave the parents with the choice of continuing under this principle or abandoning it, thus releasing the bond.

The third and fourth types of bond focus upon the strength of the relationship. An identity bond is seen where a person assimilates the qualities which are perceived in another person’s identity. An example of this is seen in the status that children acquire from their family. Here any achievement by a member of the family raises the status of the whole family. However if there is no or little response from one half of the bond, then the bond diminishes in strength. A crecive bond on the other hand grows with interaction as lives grow intertwined and as ‘we’ replaces ‘I’ in speech patterns. Here everyday activities cannot be carried out unless each person plays their part. They cite the example of an adolescent who may not take pleasure in an activity unless the parent has specifically disapproved of it. The development of the nuclear family makes the bonds between parent and child increasingly crecive and sacred from the parent’s perspective. However the child may well see their relationship more in terms of identity and contractual as they enter into adulthood. On reflection from ones own work with bereaved families, It can be seen how the sacred concept is very present for parents. Merrington (1995) found parents still manifesting intense grief reaction for difficult children who had caused great pain in their parents lives. Finkbeiner (1996) also found evidence of intertwining in grieving parents who showed confusion by

talking about their deceased child in the personal 'I' form rather than using the child's name.

Social and Communal Influences

Klass and Marwit go on to suggest that just as a child develops a sense of competence as it plays and explores, so parents gain a sense of competence as they live up to these sacred and crevice bonds. This competence is believed to be partly based upon the history of the mother and in part upon the quality of the social support system she has. Greater support leads to better interactions with the child. Anisfield and Lipper (1983) suggest that the sense of competence can be raised by compensating for the lack of social support. Interestingly Rutter (1981) found that bonding to a new born was enhanced by the support of hospital personnel who give interest, encouragement, and reassurance.

One can see that if these hypotheses are correct, then the parent who continues to show ongoing grief is helping to maintain the sacred bond and also a feeling of competence. It seems clear that where parents do gain wide social support in grief they show better signs of moving on in their lives (Merrington, 1995). Merrington found that parents who lived in close caring communities fared better in their grief as compared to those who lived in the more anonymous city or town development. The sense of competence given by wide social support may enable a parent to diminish

feelings of nurturance towards the lost child without this causing a marked drop in feelings of competence.

Inner Perceptions of Parents

Klass and Marwit draw upon Benedek's psychoanalytical work on the multiple inner representations of the child held by the parent (1959). Benedek writes that the experience of becoming a parent activates memories of how one was parented and what it was like to be a child. Parents are therefore involved with dealing with memories of being parented as well as memories of being a child. The expectations that are instilled within a parent from these memories influence their concept of parenting. Klass and Marwit talk about a sense of omnipotence within a parent that is developed in the early weeks of parenthood. This changes as the child grows, but nevertheless instills a sense of sacredness within the parent. As the years progress in parenting, there is the realisation of positive and negative aspects of the parent as perceived through the child. Klass and Marwit underscore the uniqueness of the parent-child relationship, one that is different from other human relationships.

However this does not seem sufficient to account for the long term affects of child loss in parents. Why is it that the grief reaction seems to be more prolonged than in the loss of someone else close to you? Further factors will now be suggested.

THE COMPLEXITY OF THE PARENT-CHILD BOND

The question has to be asked as to ‘what ultimately characterises the loss of a child as compared to other close losses such as a parent or spouse or a sibling’?

The case is not being made that the loss of a child is the hardest loss of all, but that this loss does show unusually long term grief effects that need to be understood. From the perspective of a parent, six areas have been identified that help to formulate a picture of the dynamic of the parent-child bond and why it seems so difficult to adjust to when it is severed.

1) A Unique Developmental History

Peppers and Knapp (1980) suggest that the foundations are laid for bonding as early as childhood, at least in fantasy form. When young girls fantasise about being a mother and play with dolls and younger siblings, each is an activity that subconsciously begins to prepare her for the future real life role of a mother (Doka, 1989).

In adulthood the development of a close affectionate bond with the child may start even before the birth of the child. In the West, parents have control over the whole process of reproduction. This means there is often extended discussion and fantasy with others about what the parent-child experience will be like. The confirmation of pregnancy is an important milestone for a parent. This encourages dialogue with a partner, parent, and friends to reflect on a range of possibilities. There is the partner's

projected reaction, the change of personal lifestyle, economic considerations, marital status, career and reaction of others around you to consider. Each thought and discussion is a link with the embryo. Once conception is known, or even beforehand, the baby signifies the potential for fulfilling dreams, starting over again, rectifying past mistakes, and putting new insights into practice.

Parents today have the opportunity to terminate the pregnancy or to willingly accept the potential birth. Accepting the pregnancy is therefore part of recognising its existence and beginning to formulate a bond with the life within. As the weeks progress, technology provides the possibility of seeing the embryo by scan and even receiving a photograph. This enables parents to begin to accept the foetus in its own right. As the months progress, the growth of the mother's womb and the experience of foetal movement all add to the mother's awareness of the affectional bond to the baby.

We need to recognise that in a modern western society there is the added depth of knowledge of the concept of pregnancy. Mothers are well informed as to the degree of physical attachment that exists between themselves and the foetus. This is increased by the union of potential mothers at prenatal classes. They also usually have time to begin to prepare for the arrival of the baby at their home. Decorating and buying utensils and clothes all add to the expectation. Each is an activity that subconsciously begins to prepare them for the future real-life role of mothers (Klaus & Kennell,

1976). Borg & Lasker (1982) have identified the depth of bonding that has been formed by the mother through observation of the grief within parents after termination early on in pregnancy.

By the time of birth we therefore have a strong degree of bonding between the parent and the baby. This bond is then enhanced at the point of birth. Often today, fathers are present at the delivery, so the experience of seeing, hearing and especially touching becomes a shared experience between the partners. From this point on, the process of caregiving develops to a greater depth.

What is clear is that no other relationship has such a protracted development well before it is initiated physically. The whole process of parenting leads to a deepening of affectionate roots with the child. This is in contrast to the child-parent bond in which the child, from an early stage is moving towards autonomy and independence from the adult. The child's history is one of gaining strength from the bond with the parent such that it can become independent enough to formulate other bonds. The link with the parent may not be severed but it is less required as maturity is reached. There are clearly different times within an affectionate bond that if it is severed can lead to differing depths of grief. For example, with the death of a parent when a child is young it is understandable that the long term impact can be considerable. The degree to which this impact has effect will depend upon the age, maturity and strength of other affectionate bonds a child might have developed. With an affectionate bond in a

marriage, the bond can become extremely entwined but it does not carry the same degree of history as with a parent-child bond.

2) The Biological Perspective

It is recognised that there is a unique factor within families when it comes to being tied together in some bonding system. The biological explanation of this is based on the principle that the key dynamic of evolution is neither individual nor even species survival, but gene survival. Thus an individual organism, who shares on average half of its genes with each of its offspring, promotes the survival of its genes by promoting the welfare of its offspring, and in this regard stands to gain more than by supporting the welfare of others who are more distantly related or not related at all. Siblings, who also share on average half of their rare genes, tend to promote the survival of their genes by promoting each other's welfare (and thus survival) and so on, to a lesser extent, with kin less closely related (Ainsworth,1991).

It seems valid to recognise that there could be biological influences which effect and shape the parents cognitive processes so as to maximise the likelihood that the parent will pass on their genetical material to subsequent generations. John Archer(1999) sees this as part of the answer to why grief is a common experience throughout all human cultures. Using an evolutionary approach, he sees organisms as being well adapted for their environments, but particular sets of reactions which contribute to this adaptation may prove maladaptive under particular circumstances. Grief is

therefore a by-product to a reaction of separation. Grief is the cost we pay for being able to love in the way we do. This implies that grief will vary according to the strength of the lost relationship. This evolutionary theory provides reason why certain classes of relationships eg. parents and offspring, should be stronger than others. Psychologically, humans exhibit high order mental processing eg. intrusive thoughts, hallucinations, feelings of change of identity. We also have a complex set of ideas about our identities. Relationships, home life, jobs, beliefs are all highly charged and resistant to change. Hence when our working models or assumptive worlds are upset, it is understandable that alarm reactions are triggered. Archer agrees with Bowlby that animals generally have evolved a reaction for separation more than for death simply because separation is far more common an experience than death. Bereavement is therefore the price we pay for a more overall reaction mechanism to separation. Separation distress is useful in the context of temporary separation. Grief occurs after death despite its being maladaptive for survival and procreation simply because of, as Parkes realised, “the cost of commitment.”

However does this mean that there is no resolution in grief? A Darwinian view of resolution would be when there is a return to normal functioning in everyday tasks, when intrusive thoughts and distress are absent, and when the person has mentally accommodated the changed reality. This is similar to the idea of detachment. Archer acknowledges the lessons learned from trauma victims in the need to continue to assimilate particular memories associated with the past life and the deceased so that

their emotional and personal significance is changed. The Dual-Process Model by Stroebe and Schut (1994) has a role to play in understanding this change in terms of confrontation, distraction or avoidance. However Archer still recognises that for some cases attachment to the deceased continues. Archer acknowledges Peppers and Knapps (1980) concept of shadow grief but also cites Nolen-Hoeksema's (1994) work which suggests that this is in fact a coping style which involves the person constantly dwelling on the loss. The rumination that results is distinct from the grief work as no progression is observed. Nolen-Hoesksema found that this accentuated the depressive mood in the depressed but with no effect upon those not depressed. This lack of resolution is partly due to the fact that the events of, for example, child loss is particularly resistant to incorporation into the parent's personal world. This is similar to trauma victims who find it difficult to accept the traumatic event and so set up an alternative cycle of uncontrollable memories and extreme avoidance. Archer reconciles this by seeing it being generated by a major discrepancy and maintained because no solution is forthcoming.

With prenatal loss, Cuisinier et al (1996) found that both subsequent pregnancy and birth of a new baby predicted a lower level of grief, as did the speed with which a new pregnancy was achieved. This is consistent with the idea that evolutionary pressure might lessen grieving if this would facilitate the rearing of more offspring.

Archer's evolutionary approach does help when looking at the loss of children of different ages. An adolescent has had a greater investment than has a one year old

child. Older children are also statistically more likely to produce offspring. So we see that the loss of a greater evolutionary benefit plus the strength of attachment will set off a greater grief alarm reaction. However we cannot assume that evolutionary responses apply to mechanisms today. Littlefield and Rushton(1986) derived a set of hypotheses about the relative severity of grief among relatives when a child dies. These work directly from functionally relevant variables such as sex, age, their kinship with the deceased and the sex, health and age of the child. Similarly Thornhill and Thornhill (1989) argued that the intensity of grief follows the loss of future fitness that the particular bereavement represents for the individual. These sources are assuming a direct link between genes and behaviour, Archer however, believes this is more likely to be due to the strength of the attachment of the bond formed, although Schatz(1986) argues that once attachment to the offspring has reached a particular level, grief will occur at a more or less constant strength. The grief reaction is in fact of no benefit to evolution unless it helps the person to produce more offspring. It seems that evolution has built in the concept of attachment for the protection of the child from threat, however the consequence of this is that grief occurs as a by-product of the design of survival. In evolutionary terms, if a person lost their only child one would expect a greater drive to want to reproduce and have another baby.

Other factors must also be taken into account, particularly mortality and culturally related issues. One would expect emotional attachment to be high in societies where mortality rates are low and parents have few infants in whom they can invest heavily.

However in societies where the mortality rate is high and where a high birth rate is found, one might expect to see a different rate of attachment.

Scheper-Hughes(1992) found among the shantytown mothers of Brazil a resistance to form attachments to newly born babies due to the low chance of survival. In a culture where there is a lack of food, clean water and the effects of pollution, parents showed a high degree of fatalism and despair. This could be seen in the lack of attachments with still births and babies that mothers felt would not survive into adulthood. The routinisation of death led to mothers seeing the death of a baby more as a minor misfortune than a tragedy. This does reveal the complexity of attachment and particularly the cultural-social influences upon it. Emotions are a part of the culture and history that a persons lives within, and it is the culture that gives us an example of how to feel. There seems to be an attitude of the parent protecting themselves from loving because of the high expectation of death. In this context the young babies are seen as transitional objects with little social status and this leads to a limited form of attachment. Yet mothers still gave names to these babies and some mothers still carried baptism records of the baby. This reveals the power of the cultural situation and the ability of a mother to adapt her perception of relationships so that she could survive in such traumatic situations. However Scheper-Hughes did find that once the baby was sufficiently seen as healthy and likely to survive, a greater degree of attachment was developed. One mother who had lost a four year old child by forceful overseas adoption, had still held on to the child's possessions and remembered her

with tears in her eyes. When death of older children occurred then the mothers would weep openly and at length express a poignant longing for the 'missing object' of their affections.

It does seem from these findings that the depth of grief would be in relation to the extent of attachment with the deceased. There is a need for further research to back these predictions particularly drawing upon a more varied cultural difference to see how attachment is formed under difficult social conditions it is therefore likely that it is a combination between biological and cultural influences which creates the desire to see children as a kind of genetical endowment for the future. This clearly is different from other affectionate relationships. Parents dwell more on the future of the child than one would do with other relationships. There is the general recognition both within a spouse relationship and a child to parent relationship that one day the partner/parent may die before the person in question. This cognitive process may not be at all well developed within the child, and can be well hidden within marriage partners but nevertheless the culture and family unit generally recognise that this is the normal life pattern. The difference for a parent is that there is the assumption that the child will outlive the parent thus maintaining some kind of continuity of the parent's heritage. In an increasingly pluralistic culture with less well defined beliefs about life after death, it is understandable that parents place a considerable amount of energy into developing offspring that will hopefully out live them. There is a need for further research into how married couples who are unable to have children, react to the

thought that their family lifeline ends with them. Perhaps the rise of interest in medical development to enable adults to have offspring by various medical techniques tells us something of the intensity to form maternal/paternal bonds.

When loss occurs therefore it is not only the loss of the past but a considerable loss for the future. One can see this in how parents continue to dwell upon their deceased child and often spend time comparing what contemporary children are doing with their lives at various stages of development as compared to what their own child would have been achieving at that time.

3) The Caregiving System

A child-to-parent attachment bond is recognised as providing a degree of security and comfort. This is unlikely in a parent-to-child bond unless a parent is expecting a child to fulfill a parental role. Another approach is to look at the caregiving system. It was thought that mothers who have the opportunity to hold their baby at birth with a positive expression tended to have better maternal care behaviour (Klaus & Kennell, 1976). Peterson and Mehl (1978) found that the most significant variable predicting differences in maternal bonding was the amount of time a mother had been separated from her baby after birth. However Sluckin, Herbert and Sluckin (1983) on their work of maternal bonding have given us a more balanced picture particularly on the narrow “window of opportunity” that Klaus and Kennell conjectured for bonding to take

place, soon after birth. Nevertheless we must not neglect the fact that bonding processes may be taking place well before birth.

This caregiving can be seen generally in the way people express warmth and protective feelings towards infants. In families it is seen between parents and children as well as sibling to sibling. It is common to see strong caregiving behaviour between grandparents and their grandchildren. Despite our general ability to care, the love within a family unit is seen to be different from our love of others. A parent does not feel the same way towards a young stranger as compared to its own child. Sluckin, Herbert and Sluckin (1983) recognise this behaviour as a maternal attachment or bond. In reality, the caregiving within a family is more diffused in that all members of a family play some role or other within the care of the individual. Families are stress-buffering units which, when functioning effectively, are able to mitigate stress of family members as familial concerns rather than as individual concerns (Boer & Dunn, 1992). This in part helps us to see how the loss of a child has such a knock-on affect upon the wider family.

Children, themselves are good examples of the caregiving system. Children show companionship with one another particularly when separation occurs between the respective parents. Children have been recognised for being able to form attachments to siblings and peers particularly when the parental attached figure is removed. Stewart (1993) found that half of his sample of three and four year olds acted to

provide reassurance, comfort, and care to their younger siblings when their mother left them for a period. However sibling relationships can be characterised not only by affection but also with a degree of hostility and rivalry. These are not seen as opposite ends of the same dimension but rather as working in a complementary way.

Caregiving is clearly a major role for a parent. Parents commit considerable time and energy into the provision of care for their children which benefits both the child and the parent. For the parent one can see how the idea of competence is developed in which an adult gains personal rewards from the caregiving process. There is, of course, a degree of caregiving in all family relationships, however it is more highly developed for a parent as compared to a sibling or a partner. Merrington (1995) found that when this role of caregiving to a child was removed, fathers found that their whole motivation for work and career development was greatly altered. Merrington agreed with Klass and Marwit that parents may well find that they seek to maintain this caregiving role after the loss of a child by becoming more altruistic. This is seen in the bereaved parents' role within support groups such as Compassionate Friends.

Bugan (1979) found that the duration and intensity of grief was a function of the degree of perceived preventability. If this is the case it seems to be challenging the parent's performance in their caregiving role. One has to acknowledge, however, that this caregiving role does not immediately re-manifest itself in the early stages of grief. Indeed Merrington found that parents acknowledged their inability to care for the

deceased's siblings in the early stages of grief. Having other children to care for did not seem to help in enabling the parent to cope with their loss. The loss may well have challenged their competence and confidence in being able to go on caring for children. However it is more likely to be due to the initial intensity of loss that makes the parent unable to concentrate on caring for anyone else at that time.

Eventually parents have to re-engage in their caregiving role, deciding whether they will become stricter or more relaxed in the care of their remaining children. If it was just the loss of the caregiving role that was the main factor in child loss, then one would expect parents with more children to be able to pick up the pieces of their lives and reinvest their energy into the remaining children. Merrington nevertheless found that young parents who had lost a baby or young child and who were able to have another child, did seem to show better recovery than parents who had lost older children. It seems that the age of the parent, or rather the length of time invested into the bond, plays a part in how the bereaved are affected long term. There is also the fact that older parents who experience loss have less time ahead of them to reinvest into child rearing. In saying all of this Merrington did still find that parents of young children still showed, even if to a lesser affect, some degree of ongoing grief. This is seen in the way that photographs are still displayed in families where a baby or young child has died even though there are now other siblings within the family. This may say more about the concept of an inner wound that will be discussed as point five in this discussion.

The bond with children that parents formulate is not straight forward. Although attention has particularly been given to the role of mothers, it is clear that fathers can also exhibit a high degree of affectionate bonding. Biologically, the care of offspring is often shared in the animal kingdom. Yet with some mammals such as monkeys and baboons the male seems to play an indirect role. Smut (1983) however found that the male baboon did act as a protector at times of danger. Even male rats, noted for their lack of care giving functions, can be induced to fulfil a care giving role (Rosenblatt et al.,1979). Merrington (1995) found that in the loss of a child, fathers were affected long term by the loss. However he did find it harder to interview fathers as compared to mothers.

4) Social Aspect of the Bond

Along with the caregiving system children do provide a range of other social functions for the parent. These are not direct aspects of the affectionate bond but nevertheless affect its outcome. Children enable parents to engage in new social relationships particularly with other parents. This begins before the birth of the child with mothers joining pregnancy groups. Also involved is a change of role as the mother-to-be leaves her work enclave and replaces it with an enclave of young parents. Her new relationships are formed because of the presence of the baby. Mother and Toddler groups, and later meetings at the school gate, begin to allow the mother particularly to see herself in a new light. Parents can often find that their friendships in life have

been formulated around other parents who have children that relate to their own. This deepens the importance of the long lasting bond between the parent and child. The letting go of one level of social interaction and formulating new friendships because of the presence of children, brings ongoing benefits to the adult. As the child develops and appears to require less attention from the parent, the presence of the child nevertheless allows the parent to fulfil a particular role within the community. Increasingly the parents see themselves performing various roles in life because they are parents. A motivation for employment and career development, the formulation of friends, the use of time and the general conversation of life are all tinted by the role of parenthood. It is with the loss of a child that all of these individual components come to be recognised together and so have such a deep impact upon the adult in their loss. Once in grief, so many aspects of the adult's life are called into question. The social and communal world around the adult serves to be a constant reminder of the loss. Researchers such as Merrington, Klass and Knapp all identify the sense of isolation that a parent feels with the loss of a child. Isolation by a community is often felt in all types of loss but it seems particularly so with child loss.

5) The Role of Kinship

Kinship relationships are another factor in the dynamic of a family, although they are closely linked with the factors already considered. Ainsworth (1991) suggests that kinship bonds endure so long due to a variety of factors. Biologically this focuses upon gene survival. An individual organism, who shares on average half of its genes

with each of its offspring, promotes the survival of its genes by prompting the welfare of its offspring. This principle generalises to kin who are less closely related than offspring. An organism stands to gain more in evolutionary terms by supporting the welfare of kin compared to those who are more distantly related or not related at all. It is surprising to find that although siblings share 50% of their genes, they are actually more different from one another than would be expected from any two people with 50% of their genes in common. This results from non genetical influences of the environment which are not shared e.g. the way a parent relates to the first child in the family as compared to the second or third.

A psychological reason for kinship bonds relates to a shared background of experience within the family. This is true for partners as well as siblings who share a large period of time within the same environment. Parents also build up an extensive experience of life with their children. A large portion of a parent's time is governed by the needs of a child. At first it may seem a twenty-four hour task, but even as the children develop, they continue to play a major part within the family. Daily routine along with key times like holidays are steered by the presence of the children. This inevitably means that when loss takes place this kin bond is particularly strong in its influence over the grief that follows.

Sociologically, cultural practices tend to encourage relationships in the kin such that one can expect a greater degree of support than would be expected from friends. So kin become particularly important in regards to one's social network.

6) The persistence of the bond

A particular important aspect of the parent-child relationship is that parents formulate expectations, plans, hopes and dreams about the child's future. Even the most unambitious parent knows that children grow up and become adults and that this should happen to their own child too. The loss of a child changes the reality of this, but the expectations typically persist in the parent's thought patterns, often for many years. The knowledge that they have lost a significant part of their hoped-for future contributes to the pain of the loss. At the same time, thoughts about the child growing, developing, and changing persist, and the internal working models underlying the bond tend to change in parallel with the child's might-have-been life. This is what underlies the concept of a continuous bond (Klass, Silverman & Nickman, 1996). Klass et al emphasise how the memories, feelings and actions that keep bereaved parents connected with a lost child are not static but developing as the child might have developed.

The persistence of a bond is not unique to the loss of a child. Klass et al also described how adoptees who had known their birth families seem to maintained an internal concept of them that evolved in a manner appropriate to what might have

been had the birth families remained intact. This can also be seen in spousal bereavement where a bereaved person seems to seek permission from the deceased partner to remarry. A fuller summary of Klass' work will be found in appendix 6.

Taking on board Klass and Marwit's concepts of sacred and crevice bonds as well as the historical, biological and social factors one can begin to see how there are multiple representations and multiple meanings. Clearly some of these factors are at play with other types of losses such as the loss of a parent or of a sibling but it seems not at such a degree as is found in parents. Sanders (1979-80) found that compared to other losses, the loss of a child produced the greatest depth of emotional factors on her grief inventory. Perhaps what characterises this type of loss is the deep wound that parents experience. Klass and Marwit see this as rather like an amputation. This kind of analogy is not reserved only for child loss as adults bereaved of partners often describe their loss as if part of themselves has died. It seems that in any particularly close and intense bond, when death occurs it is as if part of one's own identity has been destroyed. What is significant for the loss of the child is the length of time parents experience this sense of loss. Parents express the fact that once in grief they find themselves thinking about the deceased continually. It as if they have put on an extra layer of skin which is the deceased child and which therefore tinges all that they see or do. This constant thinking about the deceased is also present in other losses but not to the extent as it is for the parent-child bond. Here, the presence of the deceased

is seen in so many areas of the bereaved, that it is understandable that Klass (1996) suggests that a continuous bond endures (appendix 4).

Whether this continuous bond is present in other types of losses is unclear, but there seems to be more evidence of its existence within the parent-child bond. Although there is ongoing conversation with the deceased in various losses, when child loss occurs there is far greater room for this kind of dynamic to continue and expand. This is due to the deceased not reaching adulthood in many cases. Although parents may not have the future mapped out in any specific way for their child, nevertheless there are many assumptions that the child will reach adulthood and continue to develop as an individual. This particularly marks this bond out from other types of bonds. With the loss of a partner or a parent, although the bereaved will very naturally continue to wonder and reflect upon what might have been, there is less room for radical development as there is for the child that had so many possible areas of development ahead of them. It is this unknown that proves so difficult for parents to cope with, and therefore gives such space for the inner representation to continue far into the future life of the adult parent. Parents see this loss of potential not only as loss for another individual but also for themselves. The achievements of a parent's child are seen from a very self interested perspective. The child's achievements are seen as part of the parent's achievements in parenting. They also represent the many things that the parent have not been able to achieve but do so through the eyes of the child. All of this is taken away from the parent which leads to the loss being such an inner wound.

Learning to manage the parent-child relationship therefore is learning to understand order and control. This relationship is the main source of a person's security, comfort and nourishment in early life. As bonding relationships are formed later into adulthood there are still signs of the need for security, order and a sense of purpose. Yet when a parent encounters the loss of a child this sense of ordering of experience breaks down, thus producing vulnerability and uncertainty.

Hence one is left with a complex picture of the multiple factors influencing the bereaved parent. Bretherton (1992) shows how inner working models enable new situations to be faced with the benefit of previous experience. The working models formed early in life are assumed to remain influential throughout life. Minor changes are accommodated more or less automatically, bigger changes may cause disruption while cognitive models adapt. Child bereavement undermines such a large part of the cognitive working model that accommodation becomes extremely difficult. This inability to reorganise life into a more meaningful form leads to anxiety, depression and grief. What adds to this vulnerability is the uncertain way in which the culture at hand equally struggles to make meaning of such losses. Normally when a person is bereaved they,

" reintegrate the central purposes of their lives, so that they can once again inform life, the bereaved have at once to retrieve and consolidate the meaning of what they have lost, detach that meaning from the irretrievable past, and

reformulate the meaning so that it becomes relevant to the present"

(Weiss,1991, p.81).

However it is known that multiple factors such as sudden loss, over dependence upon the deceased and lack of support can complicate the grief reaction. The uncertainty of the loss seems to leave the bereaved with higher stress levels than other types of loss. This also applies to unintelligible events. Such events are hard to assimilate because they contradict the foundation of our security. To best protect society's members from grief would require that relationships were stable, predictable, understandable, and a high level of care given to protect the affectionate bonds that we formulate. We can see that when the loss of a child occurs it is not just an individual loss but causes multiple loss within a given community. Hence the loss of a child has all of the factors present that one would want to avoid when it comes to grief - unexplainable loss with restricted support, creating a high degree of uncertainty in the surrounding environment.

When a child dies, the loss thwarts the main motives of action within a parents life. The reason for working, building a home, planning for the future are all undermined. The loss can also seem to be unintelligible to a parent and surrounding community. This prevents a bereaved person from making sense of what has happened and contradicts the foundation of our security. On top of this many deaths of children are unexpected and are sudden. The loss seems to undermine the key relationships around

the bereaved who would normally be relied upon to offer support at difficult times.

The author found in his study in England that in many cases marriages were disfunctioning with siblings suffering the double loss of a brother or sister as well as parents lost in grief (Merrington, 1995). All of these conditions are partly independent of the personal history of the person experiencing the loss.

It is only as you collectively identify the many factors affecting the nature of the parent-child bond that a fuller view is seen of the complex picture that results from loss. Historical, biological, caregiving, social, kinship, and the expectations for the child all play a role in affecting the parent-child bond such that it endures well after the death of the child.

In the next chapter an analysis of loss in England will be discussed.

CHAPTER 5

AN ANALYSIS OF CHILD LOSS IN ENGLAND

This chapter looks at research carried out by the author (Merrington, 1995) in England looking into the long term impact of grief in parents. The questions he had in mind were to ask :

- 1) Whether the child's age had impact upon the parent's reactions.
- 2) What long term effects the loss of a child had upon parents.

At that point there was no assumption that the concept of Shadow Grief existed, although Merrington suspected that he would find long term problems within the bereaved. The data gathered was analysed particularly from a theological perspective for a Masters in Philosophy degree.

Seventy families were interviewed, scattered throughout England. In order to identify participants parents were approached via the organisation called Compassionate Friends, which is a self help support group for bereaved parents. Of 95 individuals approached, 70 people agreed to participate.

SETTING

All interviews took place in the private homes of the subjects so that they could feel relaxed, relate to the deceased's previous environment and to allow the interviewer to engage more fully with the bereaved situation. It had been estimated that

approximately ninety minutes would be needed to complete each case, however the majority took two hours.

PROCEDURE

At the interview, parents were asked to complete two questionnaires. A Grief Experience Inventory, (Sanders,1985), and Parental Inter-relationship Questionnaire (P.I.Q.) which was designed for this study by the author.

The Grief Experience Inventory, (G.E.I.), was a self-report instrument consisting of 135 true-false items and was designed to assess experience, feelings, symptoms and behaviours of individuals during the grief process (see appendix 5, p332). The items provided scores on each of 12 subscales- denial, atypical response, social desirability, despair, anger/hostility, guilt, social isolation, loss of control, rumination, depersonalisation, somatisation and death anxiety. The profile across these sub scales can be used to visualise response patterns.

The Parental Inter-relationship Questionnaire, (P.I.Q.) was designed to draw out from the participants' reactions on particular perceptions and judgements. It contained 53 questions looking at areas of social background, medical health, identity changes and relationships with the community, church and family. It was administrated as a standard structured interview, with parents responses being noted by the author.

The topics addressed in the questionnaire focused on the parental loss of children (see appendix 6). The format was designed to assist the parents in describing their experiences from the time of their child's diagnosis to the period of readjustment subsequent to death. The questions were all open-ended.

From the seventy interviewed, 57 people were willing to complete the questionnaires (35 female and 22 male). Of the children who died, twenty three were in the age group 0-2, seven were between 3-10, ten were between 11-17 and seventeen children were aged over 18 years. The type of death that the children encountered was monitored; thirty five had died from illness, three from suicide and nineteen had died through an accident. The degree of anticipation of the death was categorised as: sudden death (31 children), within twenty-four hours (3 children), between one and seven days (5 children), or after seven days (18 children).

A particular focus of the interview was the parent's reaction over time. The aim was not to interview parents in the early months of grief. Only four parents were interviewed less than two years after the death of the child. Twenty-four parents had been bereaved between 3 to 5 years, eighteen between 6 and 10 years, and ten parents had been bereaved over 10 years.

FINDINGS

1) WHETHER THE CHILD’S AGE IMPACTS UPON THE PARENT’S
REACTION

The age of the child at death was identified into four groups as can be seen in Table 4. The middle two groups are quite small, so exact probabilities are reported for statistical comparisons among the groups.

TABLE 4
THE AGE OF CHILD AT DEATH

Age at Death	Actual response (n=57)	Percentage %
0-2 years	23	40
3-10 years	7	12
11-18 years	10	18
18+ years	17	30

Three particular questions highlighted the different responses parents gave according to the age of the child at loss.

TABLE 5
PERCENTAGE YES RESPONSES TO THE QUESTION ‘WHEN ASKED,
“HOW MANY CHILDREN DO YOU HAVE,” DO YOU INCLUDE THE
DECEASED?’

	0-2 years (n=23)	3-10 years (n=7)	11-17 years (n=10)	18+ years (n=17)
YES	26%	29%	100%	76%

Table 5 shows the distribution of yes responses to the question, ‘when asked, “How many children do you have,” do you include the deceased?’ Yes responses to this question are clearly much less likely from parents bereaved of younger children. The

differences among the groups are statistically significant, chi-squared (3 = 21.035, exact $p < .001$).

The difference is probably because those parents who were bereaved of young children were usually young enough themselves to give birth to more children. Older parents were not in this position. It is notable from the interviews with younger parents that when they answered in the affirmative they tended to do so in an indirect way, however it is unclear why this is the case. When the death of particularly young children or babies takes place there is certainly less corporate knowledge, experience and shared history for the parents to relate to within the family unit and community. Young parents are also more likely to be surrounded by friends and acquaintances who are also at the child rearing stage and are therefore more cautious in talking about their loss.

TABLE 6
PERCENTAGE OF PARENTS WHO REPORTED THAT THEY HAD A
SON/DAUGHTER WHO HAD FILLED THE GAP OF THEIR LOSS

	0-2 years (n=23)	3-10 years (n=7)	11-17 years (n=10)	18+ years (n=17)
Whether son/ daughter had filled gap	74%	43%	0%	12%

Table 6 confirms that the parents who had lost younger children are themselves young enough to rear more children. The differences among the groups are again significant, chi-squared (3) = 23.601, $p < .001$. The parents who had lost children younger than ten years old are clearly much more likely to have additional children

than those who had lost older children. One would expect a bereaved person who is unable to fill the gap that has been created by death to show more rumination and a slower rate of returning back to a normal routine, as compared to those who are able to find new attachments.

There are various reasons why losing an older child is more complex. Firstly, the parent is at an older stage of life. They physically may not be in a position to have another child and emotionally do not feel able to take on the process of bringing up another child. Several English mothers had reached the age where they were going through a period of menopause. This in itself draws one's attention to a person's own ageing process. They may be also coping with their own ageing or dying parents.

Secondly, parents have placed a great degree of energy into rearing children. This has involved time, money, and has often been a prominent motivating factor when it comes to careers and work. When an older child dies it can seem that all of those years were wasted and unfruitful.

Thirdly, commitment to this affectionate bond has created a considerable volume of memories and experiences and a rich set of expectations about what the child might have been, as a consequence of the child's expressing ambitions, making the educational choices etc.. This leaves parents with a large quantity of thought process to work through. Although many of these may well be positive memories, it does

seem that the more painful memories surface and linger, increasing the degree of guilt within the older parent.

Fourthly, it is harder to project ones anger towards a baby or a young child who dies as compared to an older child who perhaps ‘should have known better.’ In England there is also the factor that parents may not now be the legal next of kin. Here the child may now have a wife, husband or partner who becomes the person responsible for the funeral, the deceased’s belongings and of the care of any of the deceased’s children. Parents who have invested years of interest and energy in their child may find that they are not consulted in dealing with the after affects of death.

‘His wife has taken the baby away so we can’t see him, I hate her’ (English interview of parent).

Finally, all parents expect to die before their children. They may have already prepared their will leaving their son or daughter as the executor and inheritor. When the tables are turned and young adults die, parents can feel cheated. They may now end up inheriting money and property from their child at a time of life when they least require it.

TABLE 7

PERCENTAGE OF PARENTS WHO REPORTED WHETHER THEY HAD
COME THROUGH BEREAVEMENT

	0-2 years (n=23)	3-10 years (n=7)	11-17 years (n=10)	18+ years (n=17)
YES	78%	100%	40%	12%
NO	17%	0%	60%	88%
NO ANSWER	5%	0%	0%	0%

Although the data reported in Table 7 does not reveal what parents actual understand by the term, ‘coming through bereavement,’ it does highlight a difference of response over the age ranges chi-squared (3) = 25.905, exact $p < .001$ (‘no answer’ responses omitted). This question relates to a further question asking whether parents still had issues to resolve relating to the loss. Here (Table 8) it is seen that children who had lost older children were more likely to respond that they still had problems to resolve relating to the loss, chi-squared (3) = 8.02, exact $p = .046$ (two ‘no answers’ responses omitted).

TABLE 8

PERCENTAGE OF PARENTS WHO REPORTED WHETHER THEY HAD
PROBLEMS STILL TO BE RESOLVED RELATING TO THEIR LOSS

	0-2 years (n=23)	3-10 years (n=7)	11-17 years (n=10)	18+ years (n=17)
YES	43%	43%	80%	82%
NO	48%	43%	20%	12%
NO ANSWER	9%	14%	0%	6%

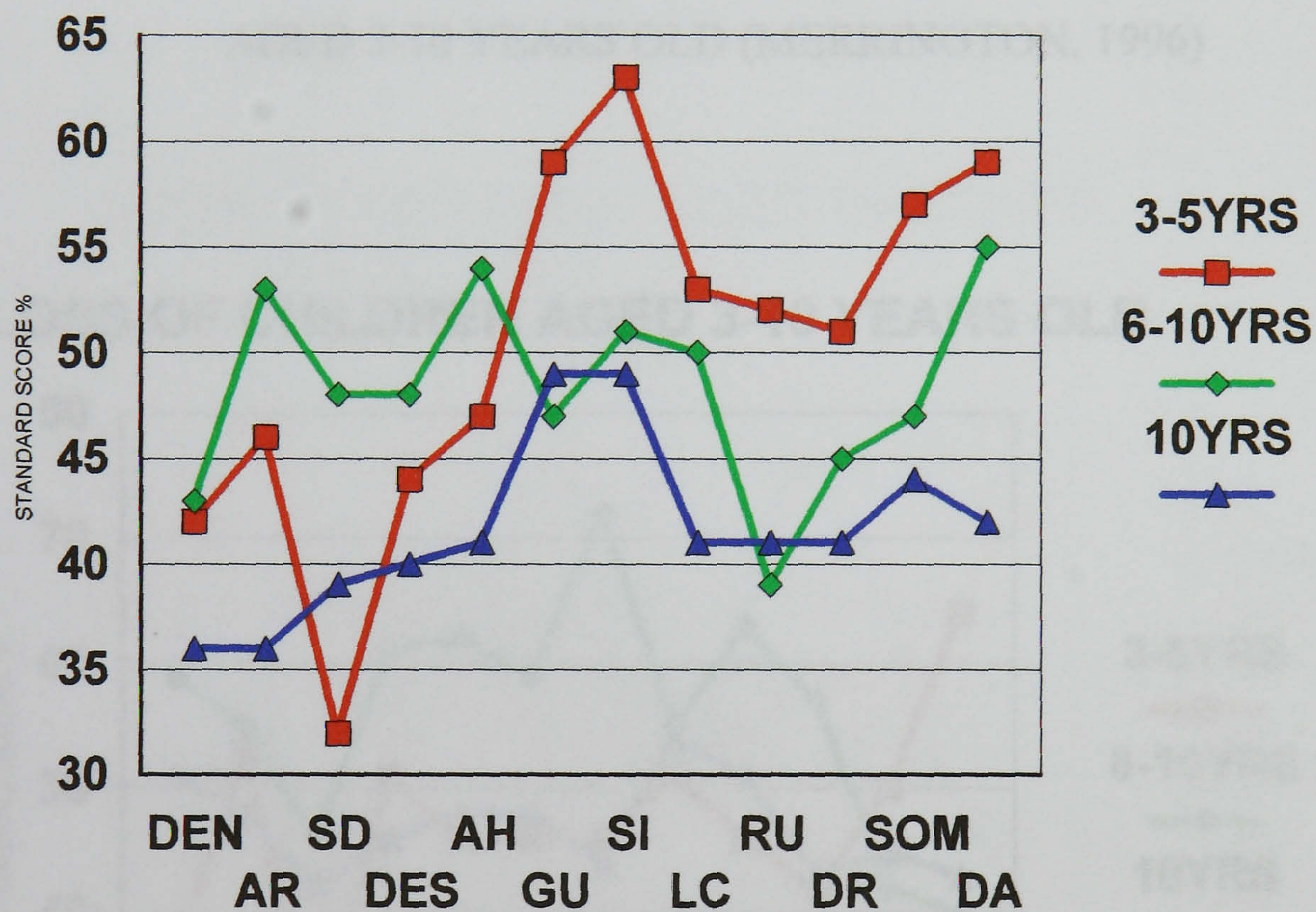
There are two reasons why there are more issues unresolved with the loss of older children. The first is increased life experience with the child. The attachment with the child has had time to develop. Parents when interviewed also expressed the difficulties of remembering times of conflict and disagreements with older children. The second reason is that over 60% of the deaths for children eleven years and over occurred by accident rather than illness. Accidental deaths carry with them more issues to be resolved relating to how the death occurred. What is required is a study that compares the loss of older children from illness with a younger age group to clarify this distinction

In regard to the Grief Experience Inventory produced originally by Sanders (1985), she compared the scores of those bereaved who had suffered the loss of a child, spouse or parent (for a summary of the inventory, sub-scales etc. see appendix 7). Sanders found that the loss of a child produced significantly higher scores on the GEI than did the loss of a spouse or parent. When analysing a specific case study of a grieving mother with the loss of a fifteen year old son, Sanders found that the GEI showed a picture of intense grieving. Somatisation was the highest subscale with the score which indicated the degree of physical stress suffered. Despair and Depersonalisation were also particularly high which pointed to a degree of feelings of unreality. Anger was evident along with loss of control and guilt. This collectively paints a picture of deep and painful bereavement. When analysing the data for parents

bereaved of children whose age ranged from premature to two years old, it was found that the grief subscales decreased over a period of time as can be seen in figure 2.

FIGURE 2
GRIEF EXPERIENCE INVENTORY PROFILE FOR THE LOSS OF CHILDREN
AGED 0-2 YEARS (ENGLISH DATA- MERRINGTON, 1996)

LOSS OF CHILDREN AGED 0-2 YEARS OLD

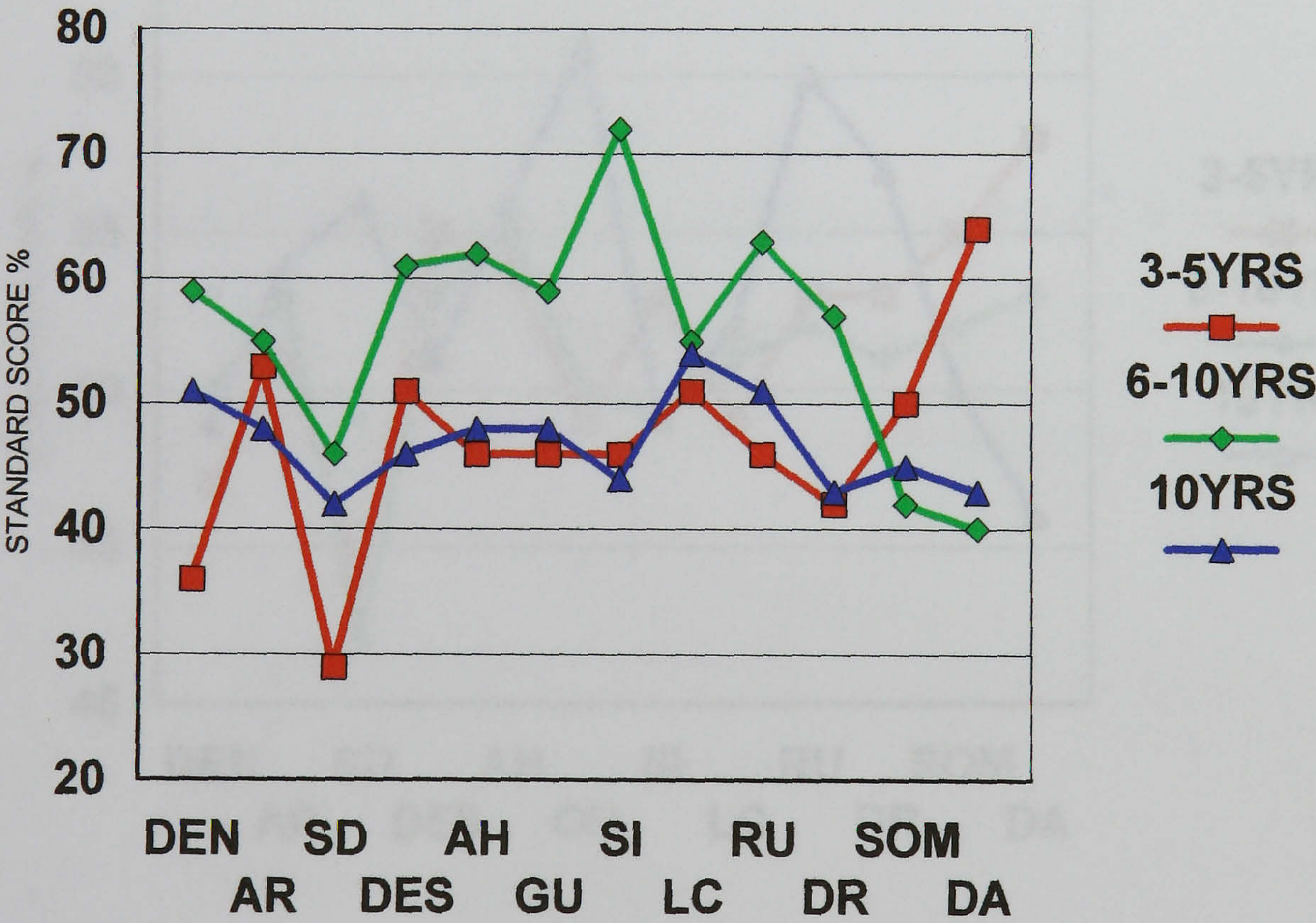


CODE	DEN	-	DENIAL
	AR	-	ATYPICAL RESPONSE
	SD	-	SOCIAL DESIRABILITY
	DES	-	DESPAIR
	AH	-	ANGER/ HOSTILITY
	GU	-	GUILT
	SI	-	SOCIAL ISOLATION
	LC	-	LOSS OF CONTROL
	RU	-	RUMINATION
	DR	-	DEPERSONALISATION
	SOM	-	SOMATISATION
	DA	-	DEATH ANXIETY

There was a similar picture with the data on the loss of children aged from three to ten years old (figure 3). What is surprising is how the grief levels are particularly high over the period of six to ten years. To clarify this one would need to carry out a longitudinal survey of the same parents over a broad period of time.

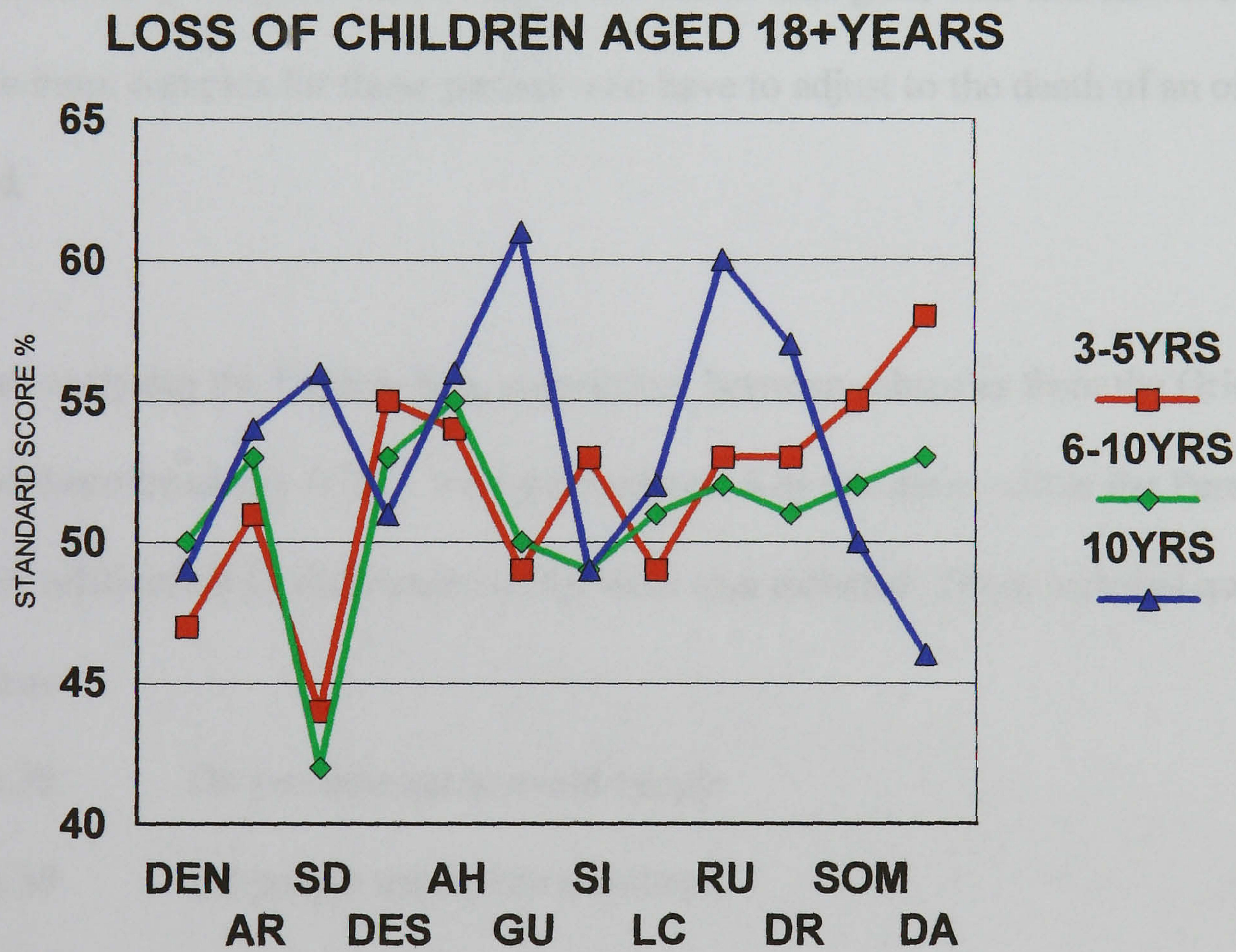
FIGURE 3
GRIEF EXPERIENCE INVENTORY PROFILE FOR THE LOSS OF CHILDREN
AGED 3-10 YEARS OLD (MERRINGTON, 1996)

LOSS OF CHILDREN AGED 3-10 YEARS OLD



When looking at the subscales for those bereaved of children over the age of eighteen years, a more complex picture was found (figure 4). Over the years factors such as rumination, guilt and social isolation remained particularly high.

FIGURE 4
GRIEF EXPERIENCE INVENTORY PROFILE FOR THE LOSS OF CHILDREN
AGED 18+ YEARS (MERRINGTON, 1996)



From figure 4, there appears to be a different reaction for bereaved parents who have had a more time to develop a relationship and to accumulate a greater history with their children as compared to those parents who lost very young children.

This seems to reflect how an affectionate bond between a parent and its child grows and deepens over increased contact. The outcome of the loss of the child clearly leaves the parent with considerable emotional trauma which is not easily dealt with even over a period of years. The psycho-social affects of the loss of a child of any age is considerably weighed on the side of loss rather than gain. This loss however seems to be more complex for those parents who have to adjust to the death of an older child.

On re-analysing the English data, correlation between subscales from the Grief Experience Inventory (GEI) were investigated. Key questions within the Parental Inter-relationship Questionnaire (PIQ) were also included. These included questions such as:

- | | |
|---------|--|
| Que.29 | Do you attempt to avoid people |
| Que.30 | Do people attempt to avoid you |
| Que. 60 | Have you a special object |
| Que. 61 | Do you feel you have come through bereavement |
| Que. 62 | Do you still feel you have problems to resolve |

Correlations between the grief subscale scores are shown in Table 9. It is immediately apparent that the social desirability subscale does not correlate significantly with any of the other subscales, indicating that the parents' responses were substantially unaffected by a wish to provide socially desirable answers to the questions.

TABLE 9
CORRELATIONS AMONG GRIEF SUB-SCALES (re-analysed data collected by Merrington 1999)

	Loss of control	Despair	Social desirability	Anger/ hostility	Guilt	Social isolation	Rumination	Deperson- alisation	Somatis- ation	Death anxiety	Denial	Atypical response
Loss of control	1.00											
Despair	-.63**	1.00										
Social desirability	-.09	-.12	1.00									
Anger/hostility	.17	.50**	-.14	1.00								
Guilt	.37	.51**	.06	.34**	1.00							
Social isolation	.17	.52**	-.08	.40**	.24	1.00						
Rumination	.37**	.59**	.11	.11	.45**	.30*	1.00					
Depersonalisation	.55**	.73**	.02	.29*	.38**	.37**	.63**	1.00				
Somatisation	.34*	.71**	-.03	.60**	.42**	.35*	.34**	.52**	1.00			
Death anxiety	.21	.19	-.23	.10	.09	-.01	-.17	.05	.09	1.00		
Denial	.11	.06	.21	-.12	-.12	-.08	.09	-.10	-.14	-.62**	1.00	
Atypical response	.32	.40**	-.29	.51**	.26	.35*	.09	-.10	.51**	.13	-.10	1.00

• p<.05, ** p<.01

•

The Death Anxiety and Denial were significantly correlated with one another, but neither was highly correlated with any of the other subscales. The correlation between these two subscales was one of the highest correlations among the subscales, suggesting that they may be measuring more or less the same underlying factor.

The other six subscales, Loss of Control, Despair, Anger/hostility, Guilt Social Isolation, Rumination, Depersonalisation, Somatisation and Atypical Response, form a cluster of inter-related measures. Despair seems to be at the core of this cluster in the sense that it correlated particularly highly with the others.

Correlations between selected items from the parental inter-relationship questionnaire are shown in table 10 (since the items have yes/no responses, the correlations are phi coefficients). It is clear that the responses to question 61, reflecting whether the parents feel they are still working through their loss, are strongly associated with responses to question 62 on whether they feel they still have problems to resolve. In addition, responses to question 29 on parents avoiding people is very associated with responses to question 30 on people tending to avoid the parents. Neither of these associations is surprising.

TABLE 10

CORRELATIONS BETWEEN THE SELECTED PARENTAL
INTER-RELATIONSHIP QUESTIONNAIRE ITEMS

	Working through loss	Still with problems	Do you avois people	Do people avoid you	Have you a special object
Working through loss	1				
Still with problems	-.47**	1			
Do you avois people	-0.17	0.06	1		
Do people avoid you	-0.03	0	.72**	1	
Have you a special object	0.1	0.03	0.14	0.03	1

Correlations between grief subscales and the parental inter-relationship questionnaire items are shown in table 11 (since the questionnaire items have yes/no responses, these tests are formally equivalent to t tests, but the correlation coefficients are useful descriptively, and significant levels are identical to the two kinds of test). None of the questionnaire items is associated with the social desirability scale.

Question 29 on parents avoiding people and question 30 on people tending to avoid the parents have a very similar pattern of relationship with the grief experience subscales. They relate only to the Loss of Control subscale. Their association with the social isolation subscale is just below the level for statistical significance. Responses to Question 60 on having a special object are strongly related only to rumination and depersonalisation, suggestive of a particular kind of severe reaction. Despite their significant association with one another, Question 29 and Question 30 have somewhat different patterns of association with grief subscales. They are both associated with guilt and with social isolation.

Question 61, reflecting whether the parents feel they are still working through their loss, and Question 62 on whether they feel they still have problems to resolve, have similar but not identical patterns of association with grief subscales. They are both significantly correlated with the Despair, Somatisation and Atypical Response subscales and their correlations with Depersonalisation are not greatly different even though one falls just below significance. However, Question 62 on still having problems to resolve is significantly correlated with Social Isolation and with Guilt, but Question 61 is not. Thus these two questions, and the different subscales, may be tapping distinctive aspects of the Grief experience.

TABLE 11
CORRELATIONS BETWEEN GRIEF SUBSCALES AND THE PARENTAL
INTER-RELATIONSHIP QUESTIONNAIRE

	Working through loss	Still with problems	Do you avoid people	Do people avoid you	Have you a special object
Loss of control	0.19	-0.07	-.45**	-.31*	0.24
Despair	.29*	-.43**	-0.16	-0.25	0.27
Social desirability	-0.12	-0.1	-0.1	0.11	0.13
Anger/hostility	0.27	-0.19	-0.18	-0.1	0.04
Guilt	0.11	-0.34*	-0.11	-0.07	0.25
Social isolation	0.09	-.36*	-0.22	-0.24	0.13
Rumination	0.15	-0.25	0.05	-0.2	.51**
Depersonalisation	.30*	-0.25	-0.2	-0.23	.47**
Somatisation	.42**	-.32*	-0.13	-0.11	0.2
Death anxiety	-0.25	0.11	0.09	0.01	0.04
Denial	.37*	-0.11	0.18	0.25	0.13
Atypical response	-.36*	-.36*	-0.19	-0.21	-0.02

The despair sub-scale measures the mood state of the respondent, characterised generally by pessimistic outlook on life, feelings of hopelessness or worthlessness, slowing of thoughts or actions, and low self-esteem. These correlations indicate that

the bereaved are showing signs of being preoccupied, turned inward and dysphoric. The fact that these factors seem to be particularly present years later in parents who have lost older children reveal how parents have to grapple with depression, anxiety, fear, anger and hopelessness over a long period of time. It seems that these factors are not revealing a particular characteristic of bereaved parents but rather the fact that parents experience the breadth of grieving factors like any other loss. However the important point is the fact that these feelings still exhibit themselves several years later. There appears to be no evidence that these grief factors totally diminish within a parent with older children.

There appears to be a homogenous measurement here of the ongoing experience of grief within the parent. Rather than the bereaved parent experiencing specific grief factors at certain times, they seem to be exhibiting more of a general fog of emotional factors which remain present over many years. It must be recognised that another interpretation of the interdependence among the sub-scales is that they are not measuring different aspects of grief. However this does not greatly detract from the conclusion of long-lasting intense grief responses.

It is interesting to note the particularly high level of correlation between rumination and holding on to special objects of the deceased. One would expect that those parents who remain focused upon artefacts etc. of the deceased would be more inclined to dwell upon their loss. This brooding on thoughts of the deceased also

shows a close link with guilt and depersonalisation. Sanders (1985) suggested that one would see high levels of depersonalisation particularly when the loss is unexpected or when a person feels a sense of loss of control. This seems to be especially true with the loss of children. This is consistent with research by Dyregrov and Matthiesen (1991) who found that parents showed better rates of recovery if they eventually returned to work rather than remaining within the home surrounded by the child's belongings, photographs etc.

2) PARENTS EXHIBITING DIFFICULTIES OVER THE YEARS

From the parents who filled in the two questionnaires and were interviewed, it seemed that parents were finding it difficult to move on from the loss. To assist in the interpretation of the scores on the GEI, the data were examined to see how the GEI subscale scores related to key questions in the Parental Interrelationship Questionnaire. Analyses of variance were comparing scores on sub-scales of grief experience, between those who responded yes and those who responded no to items in the Parental Interrelationship Questionnaire. The results can be found in tables 12-23. It is notable that none of these questions from the PIQ were significantly related to the social desirability subscale score. This implies that responses to the questions were not simply a consequence of the parents' perceptions of what was the most desirable response.

TABLE 12

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.61 ‘HAVE YOU COME
THROUGH BEREAVEMENT’

SUB-SCALES	MEANS FOR YES	MEANS FOR NO	
ATYPICAL RESPONSE	6.4	8.3	F (1,41) = 5.92, P=0.02 *
LOSS OF CONTROL	5.3	6.1	F (1,46) = 1.72, P=0.20
DESPAIR	5.4	8	F (1,45) = 4.2, P=0.05 *
SOCIAL DESIRABILITY	4.5	4.5	F (1,38) = 0.01, P=0.92
ANGER/HOSTILITY	4.6	5.7	F (1,47) = 3.55, P=0.06
GUILT	2.1	2.4	F (1,48) = 0.63, P= 0.43
SOCIAL ISOLATION	2.3	2.6	F (1,48) =0.4, P=0.53
RUMINATION	4.5	5.3	F (1,44) = 0.99, P=0.33
DEPERSONALISATION	4.1	5.3	F (1,49 = 4.67, P=0.04 *
SOMATISATION	4.4	7.3	F (1,47) = 9.97, P=0.003 **
DEATH ANXIETY	6.7	5.6	F (1,45) = 2.87, P=0.097
DENIAL	1.7	3	F (1,47) =7.31 P=0.01 **

For participants who responded that yes they have come through their bereavement, the mean atypical response score was 6.4, compared to 8.3 for those who felt they had not worked through their loss (Table 12). This was statistically significant with $p=0.02$. Other sub-scales that showed significant relationships to this question included despair (mean of 5.4 for yes compared to 8.0 for no, $p=0.05$), depersonalisation (means of 4.1 for yes compared to 5.3 for no, $p=0.03$), and especially the factors of somatisation (means of 4.4 for yes compared to 7.3 for no, $p=0.003$), and denial (means of 1.7 for yes compared to 3.0 for no, $p=0.01$). This tells us that the somatisation and denial scores particularly differ according to how people coded on their answers about having worked through their grief. The inability to come to terms with the loss along with ongoing somatic problems shows that these bereaved parents are struggling to adjust to this loss, but it is noteworthy that this

struggling to come through bereavement is not associated with feelings of guilt, anger or rumination.

TABLE 13

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.62 ‘DO YOU STILL HAVE PROBLEMS TO RESOLVE’

SUB-SCALES	MEAN FOR YES	MEAN FOR NO	PROBLEMS STILL TO RESOLVE
ATYPICAL RESPONSE	8	5.8	F (1,39) =5.88, P=0.02 **
LOSS OF CONTROL	5.8	5.5	F (1,45) =0.25, P=0.62
DESPAIR	7.9	3.9	F (1,44) =9.72, P=0.003 **
SOCIAL DESIRABILITY	4.6	4.3	F (1,37) =0.40, P=0.53
ANGER/HOSTILITY	5.4	4.5	F (1,45) =1.76, P=0.19
GUILT	2.6	1.4	F (1,46) =5.89, P=0.02 **
SOCIAL ISOLATION	2.9	1.5	F (1,46) =6.97, P=0.01 **
RUMINATION	5.3	3.8	F (1,43) = 2.90, P=0.10
DEPERSONALISATION	5	3.8	F (1,47) =3.13, P=0.08
SOMATISATION	6.4	4	F (1,45) =5.12, P=0.03 **
DEATH ANXIETY	6	6.6	F (1,43) =0.51, P=0.48
DENIAL	2.5	2	F (1,45) =0.57, P=0.45

Looking at Question 62 which relates to whether parents felt that they still had problems to resolve relating to the loss, revealed statistically significant differences with grief sub-scales atypical response (means of 7.9 for yes compared to 5.8 for no, p= 0.02), despair (means of 7.8 for yes compared to 3.9 for no, p=0.003), guilt (means of 2.6 for yes compared to 1.4 for no, p=0.02), social isolation (means of 2.9 for yes compared to 1.5 for no, p=0.01), and somatisation (means of 6.4 for yes compared to 4.0 for no, p=0.03 (Table 13). These grief factors of despair, guilt, social isolation and somatisation paint a picture of a parent who seems trapped within their grief. Feelings of loss of control, death anxiety and denial were clearly not associated with still having problems to resolve.

TABLE 14

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.29a ‘DO YOU ATTEMPT
TO AVOID PEOPLE AT WORK’

SUB-SCALES	MEAN FOR YES	MEAN FOR NO	DO YOU AVOID PEOPLE AT WORK
ATYPICAL RESPONSE	8.5	6.9	F (1,35) = 1.26, P=0.29
LOSS OF CONTROL	8.5	5.4	F (1,38) =9.8, P=0.003 *
DESPAIR	8.3	6.1	F (1,37) =0.97, P=0.33
SOCIAL DESIRABILITY	5	4.5	F (1, 32) =0.33, P=0.57
ANGER/HOSTILITY	6	4.8	F (1,38) =1.21, P=0.27
GUILT	2.8	2.2	F (1,38) =0.43, P=0.52
SOCIAL ISOLATION	3.5	2.3	F (1,38) =1.99, P=0.17
RUMINATION	4.5	4.9	F (1,37) =0.08, P=0.78
DEPERSONALISATION	6	4.5	F (1,38) =1.65, P=0.21
SOMATISATION	7	5.5	F (1,38) =0.67, P=0.42
DEATH ANXIETY	5.3	5.9	F (1,30) =0.30, P=0.59
DENIAL	1.8	2.8	F (1,38) =1.21, P=0.28

For participants who responded that they attempted to avoid people at work, the loss of control score was 8.5 for yes compared to 5.4 for no for those who responded that they did not attempt to avoid people. This was statistically significant $F (1,38) =9.80$, $p=0.003$ (Table 14). This might be measuring part of the tension that exists within some bereaved parents as they attempt to cope with a work situation. Avoiding people at work is a way of not being put in a difficult situation which neither the bereaved parent or the work colleague knows how to deal with. One of the fears that parents have is that when they begin to talk about their loss, they are anxious about how they will behave emotionally. Their inability to control their emotions tends to encourage them to withdraw from social discussion. By avoiding contact one is also lessening the chance of something awkward being said. Parents readily shared at

interview the level of conversations that have hurt them at work or in the neighbourhood:

‘It could be worse.’

‘Call me if you want anything.’

‘Try and be wise.’

‘I know because I lost my dog.’

‘At least he was sixteen.’

‘He was just a trouble to you.’

‘It will get better.’

‘Time heals.’

‘You need to pull yourself together, put it behind you.’

In the interviews, men particularly expressed that work helped them because it kept them active and less apathetic. A daily regular commitment provided a role for a bereaved parent, compared to being at home, engulfed in memories. This however does not mean that emotions were totally suppressed. Several men echoed that they had often felt like crying at work.

‘Feelings would suddenly come flooding in and catch you unawares
(interview).’

Wanting to avoid people at work was not associated with potentially more serious attributes of grief experience, such as guilt, somatisation and death anxiety.

TABLE 15

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.29b ‘DO YOU ATTEMPT
TO AVOID PEOPLE IN THE NEIGHBOURHOOD’

SUB-SCALES	MEAN FOR YES	MEAN FOR NO	DO YOU AVOID PEOPLE IN THE NEIGHBOURHOOD
ATYPICAL RESPONSE	8.8	7.1	F (1,41) = 1.84, P=0.18
LOSS OF CONTROL	7.6	5.5	F (1,46) =4.75, P=0.03 *
DESPAIR	9.8	6.3	F (1,45) =2.92, P=0.095
SOCIAL DESIRABILITY	4.2	4.6	F (1, 38) =0.44, P=0.51
ANGER/HOSTILITY	5.8	5.1	F (1,46) =0.49, P=0.49
GUILT	2.6	2.2	F (1,47) =0.0.24, P=0.62
SOCIAL ISOLATION	3.6	2.3	F (1,47) =2.80, P=0.10
RUMINATION	6.4	4.7	F (1,44) =1.84, P=0.18
DEPERSONALISATION	6.2	4.5	F (1,47) =2.65, P=0.11
SOMATISATION	7	5.7	F (1,47) =0.62, P=0.43
DEATH ANXIETY	6.2	6.3	F (1,45) =0.003, P=0.95
DENIAL	1	2.5	F (1,46) =3.19, P=0.08

For participants who responded that they avoided people in the neighbourhood, the loss of control score was 7.6 for yes compared to 5.4 for no for those who said that they did not avoid people in the neighbourhood. This was significant, $F (1,46) =4.75, P=0.03$ (Table 15). When one compares the loss of control responses a picture emerges that seems to show that both the bereaved parent and those surrounding them in the community, find it difficult to cope with face to face encounters. The broad picture arising from this analysis of Question 29b is very similar to the analysis of Question 29a, which is not surprising as both relate to the avoidance of others.

TABLE 16

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.60 ‘HAVE YOU A SPECIAL
OBJECT OF THE DECEASED’

SUB-SCALES	MEAN FOR YES	MEAN FOR NO	HAVE YOU A SPECIAL OBJECT OF THE DECEASED
ATYPICAL RESPONSE	7.3	1.2	F (1,42) = 0.02, P=0.89
LOSS OF CONTROL	4.9	6	F (1,47) =2.85, P=0.09
DESPAIR	4.9	7.4	F (1,46) =3.57, P=0.07
SOCIAL DESIRABILITY	4.3	4.7	F (1, 39) =0.69, P=0.41
ANGER/HOSTILITY	5.1	5.2	F (1,48) =0.06, P=0.81
GUILT	1.6	2.5	F (1,49) =3.18, P=0.08
SOCIAL ISOLATION	2.1	2.6	F (1,49) =0.85, P=0.36
RUMINATION	2.8	5.8	F (1,45) =15.97, P=0.0002 **
DEPERSONALISATION	3.1	5.3	F (1,50) =14.08, P=0.0005 **
SOMATISATION	4.8	6.3	F (1,48) =2.01, P=0.16
DEATH ANXIETY	6.1	6.3	F (1,46) =0.07, P=0.79
DENIAL	2	2.5	F (1,48) =0.81, P=0.37

From the question which asked whether parents had a special object belonging to the deceased, rumination and depersonalisation scores revealed very significant F probabilities of 0.0002 and 0.0005 respectively (Table 16). If one is spending time focusing upon objects that belonged to the deceased or sitting in the deceased’s bedroom, then it is understandable that the bereaved would be ruminating and dwelling upon the loss. It was very common to notice that as one entered the home of those to be interviewed, that many had prominently displayed pictures and photographs of the deceased child. Although no measurement was taken of this, it seemed from observation, to be unrelated of the age of the child deceased. Depersonalisation would also relate to this. This is usually a sign of a deep and intense form of bereavement. The idea of not concentrating well or feeling that one is going through the motions would show a bereaved parent focusing extensively upon

their loss. On the other hand retaining a special object of the deceased was clearly not associated with the atypical response subscale, nor with anger, social isolation, death anxiety, or denial.

TABLE 17

CORRELATION FOR QUE.7 ‘TIME SINCE DEATH’

SUB-SCALES	MEAN FOR 0-2 YEARS	MEAN FOR 3-5 YEARS	MEAN FOR 6-10 YEARS	MEAN FOR 10+ YEARS	TIME SINCE DEATH
ATYPICAL RESPONSE	7	6.7	8.9	6.1	F (3,39) = 2.59, P=0.07
LOSS OF CONTROL	4	6	5.5	6	F (3,44) =0.87, P=0.46
DESPAIR	8.5	5.8	7.6	7	F (3,43) =0.59, P=0.63
SOCIAL DESIRABILITY	4.5	4.6	4.5	4.9	F (3,36) =0.19, P=0.90
ANGER/HOSTILITY	6.8	4.6	5.9	4.9	F (3,45) =1.92, P=0.14
GUILT	3.5	2.1	2.1	2.4	F (3,46) =0.89, P=0.46
SOCIAL ISOLATION	1.3	2.1	3	2.8	F (3,46) =1.39, P=0.26
RUMINATION	3.5	4.9	4.5	5.9	F (3,42) =0.67, P=0.58
DEPERSONALISATION	4	5	4.6	4.8	F (3,47) =0.25, P=0.86
SOMATISATION	9.7	5.1	6.2	6	F (3,45) =1.58, P=0.21
DEATH ANXIETY	5.7	6.9	5.8	5.5	F (3,43) =1.03, P=0.39
DENIAL	2.8	2.2	2.6	2	F (3,45) =0.30, P=0.82

No significant correlations were observed between the grief experience subscale and the question relating to the time since death (Table 17). This is not surprising if the bereaved do continue to show long term signs of grieving for the deceased child across the range of elements of grief experience.

TABLE 18

CORRELATION FOR QUE.45 MARRIAGE DETERIORATION

SUBS-CALES	MEAN FOR IMPROVED	MEAN FOR SAME	MEAN FOR DETERIORATION	MARRIAGE DETERIORATION
ATYPICAL RESPONSE	6.2	7.3	8.7	F (2,39) = 2.11, P=0.13
LOSS OF CONTROL	5.2	5.9	5.8	F (2,42) =0.38, P=0.68
DESPAIR	6.9	5.7	9.4	F (2,41) =2.81, P=0.07
SOCIAL DESIRABILITY	5.1	4.8	4	F (2,36) =2.04, P=0.15
ANGER/HOSTILITY	4.9	4.7	6.4	F (2,43) =2.65, P=0.08
GUILT	2.5	2.2	2.3	F (2,45) =0.07, P=0.94
SOCIAL ISOLATION	2.8	2	3.1	F (2,43) =1.89, P=0.16
RUMINATION	4.4	4.9	4.7	F (2,40) =0.08, P=0.92
DEPERSONALISATION	4.9	4.4	5.5	F (2,44) =1.12, P=0.34
SOMATISATION	5.3	5.4	7.7	F (2,44) =1.97, P=0.15
DEATH ANXIETY	7.4	5.7	6.4	F (2,43) =2.07, P=0.14
DENIAL	1.7	2.6	2.5	F (2,44) =1.04, P=0.37

No particular variation in grief sub-scales scores were found relating to the answers to Question 45 on the deterioration of a bereaved person’s marriage(table 18). One might have thought that marriage breakdown would have been seen relating particularly to some of the long term grief factors such as despair and rumination. Although acknowledging the condition of ones marriage is a difficult thing to do within the questionnaire setting, nevertheless a relationship was shown to exist Fifty percent of parents in the 6-10 years since loss group expressed that their marriage had deteriorated. What is unknown is whether deterioration would have taken place irrespective of the loss of a child. Parents individually were able to acknowledge what condition their marriage was in before the loss.

‘We had a good marriage and a happy start. It is only because of this we feel we’ve come through such a bad patch.’

‘Death creates a sort of distance between you and your partner that creates a strain.’

‘Our marriage had cracks but our daughter cemented over them until she died. The other child was hyperactive, the father felt he had been left with the booby prize.’

‘When my son was in hospital I wanted to stay with him but my husband not liking hospitals wanted constantly to come home. This created conflict and later I felt bitter and angry towards him,’ (Merrington, 1996).

TABLE 19
ANOVA ON GEI SUB-SCALE SCORES FOR QUE.19 ‘ALCOHOL USE’

SUB-SCALES	MEAN FOR YES	MEAN FOR NO	ALCOHOL USE
ATYPICAL RESPONSE	7.1	7.9	F (1,41) = 0.77, P=0.39
LOSS OF CONTROL	5.9	5.7	F (1,45) =0.08, P=0.78
DESPAIR	6.3	8.1	F (1,44) =1.75, P=0.19
SOCIAL DESIRABILITY	4.6	4.5	F (1,37) =0.10, P=0.75
ANGER/HOSTILITY	5.1	5.2	F (1,46) =0.02, P=0.90
GUILT	2.2	2.6	F (1,48) =0.90, P=0.35
SOCIAL ISOLATION	2.1	3.2	F (1,47) =3.98, P=0.05 *
RUMINATION	4.7	5.8	F (1,43) =1.67, P=0.20
DEPERSONALISATION	4.6	5.2	F (1,48) =0.76, P=0.39
SOMATISATION	5.6	6.8	F (1,46) =1.10, P=0.30
DEATH ANXIETY	6.2	6.2	F (1,45) =0.01, P=0.95
DENIAL	2.5	2.2	F (1,46) =1.34, P=0.56

TABLE 20

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.19B CHANGE IN

ALCOHOL CONSUMPTION

SUBSCALES	MEAN FOR INCREASE	MEAN FOR SAME	MEAN FOR DECREASE	
ATYPICAL RESPONSE	9.8	6.4	6.2	F (2,29) = 5.46, P=0.01 *
LOSS OF CONTROL	6.7	5.7	5.3	F (2,31) =1.02, P=0.37
DESPAIR	8.9	5.5	5.5	F (2,29) =2.41, P=0.11
SOCIAL DESIRABILITY	4.7	4.6	4.5	F (2,25) =0.04, P=0.96
ANGER/HOSTILITY	6.1	4.8	5.1	F (2,32) =1.28, P=0.29
GUILT	2.4	1.9	2.5	F (2,33) =0.19, P=0.83
SOCIAL ISOLATION	2.4	1.9	2.5	F (2,33) =0.56, P=0.58
RUMINATION	5.6	4.3	4.3	F (2,29) =0.69, P=0.51
DEPERSONALISATION	5.3	4.4	4.4	F (2,34) =0.66, P=0.52
SOMATISATION	7.8	5	5	F (2,31) =2.15, P=0.13
DEATH ANXIETY	6.6	6.6	4.3	F (2,31) =2.36, P=0.11
DENIAL	3.3	2.1	3	F (2,32) =1.49, P=0.24

The social isolation score differed significantly according to how people responded to question 19 about whether they drank alcohol. The social isolation score was higher for those who did not use alcohol (table 20). It is unclear whether this is showing that the drinking of alcohol is more of a social activity, although one would have suspected that the more isolated a person finds themselves the more likely they would be to use alcohol as a substitute.

TABLE 21

ANOVA ON GEI SUB-SCALE SCORES FOR QUE.15 ‘WHEN ASKED HOW
MANY CHILDREN DO YOU HAVE, DO YOU INCLUDE THE DECEASED’

SUB-SCALE	MEAN FOR YES	MEAN FOR NO	MEAN FOR INDIRECTLY YES	
ATYPICAL RESPONSE	7.4	7.8	6.5	F (2,41) = 0.65, P=0.53
LOSS OF CONTROL	5.8	5.1	5.8	F (2,46) =0.27, P=0.76
DESPAIR	7.3	3.9	6.7	F (2,45) =1.84, P=0.17
SOCIAL DESIRABILITY	4.8	4.2	4.2	F (2,38) =1.24, P=0.30
ANGER/HOSTILITY	5.5	4.8	4.7	F (2,47) =0.69, P=0.51
GUILT	2.7	1.5	1.7	F (2,48) =2.76, P=0.07
SOCIAL ISOLATION	2.8	1.4	2.2	F (2,48) =1.91, P=0.16
RUMINATION	5.7	3.2	3.6	F (2,44) =4.50, P=0.02 **
DEPERSONALISATION	5.4	2.6	4.3	F (2,49) =6.20, P=0.004 **
SOMATISATION	6.5	4.6	5.1	F (2,47) =1.32, P=0.28
DEATH ANXIETY	5.3	7.4	7.8	F (2,45) =7.80, P=0.001 **
DENIAL	2.9	0.8	1.8	F (2,47) =5.10, P=0.01 *

Table 21 shows that grief sub-scales depersonalisation, death anxiety and denial differ according to how people responded to Question 15 on whether they include the deceased when asked about how many children that they have within their family. The data reveals that parents who included the deceased in their answer show a tendency to exhibit more rumination, depersonalisation, death anxiety and denial. Sanders (1985) recognised that death anxiety often has a higher correlation with the denial scale than with other Grief Experience Inventory scales. The ongoing acknowledging of the deceased within the parent’s lives reveals how the issue of the deceased is at the forefront of their thoughts.

Although there has been some agreement with the findings of Sanders (1985) within the English data it has to be acknowledged that there is a major flaw within the

sample base. All those who participated in the research were contacted through the self help group Compassionate Friends. The conclusions drawn therefore reflect those who seek out support. This form of self help may be very beneficial in the initial stages of grief but raises questions of whether such support actively encourages prolonged grief. The group dynamic of sharing your story each time one attends the group may hinder parents from moving on with their lives. One might expect such a group to show signs of prolonged rumination. Over-focusing upon the events of the loss may well heighten factors such as despair, guilt, social isolation and somatisation. Because of the nature of the sample this analysis may fail to reflect the behaviour of parents who either recover adequately such that they require no further support, or who continue to show problems but do not join self help groups. It is possible that 'Shadow Grief' may be present in all parents who loose children but what is being seen in the 'Compassionate Friends' group is more of a dysfunctional form of 'Shadow Grief.'

A second area of weakness of the data is that there is a too small a sample base of the different age groups. It would be beneficial to compare the effects of child loss of parents with a group involving the loss of young adults to compare how this relates to the loss of teenagers. There is also the weakness of taking a snap shot of the effects of bereavement within the parents at one period in time What is required to bring validity to the analysis is a longitudinal study of bereaved parents from a broader sample base

over a longer period of time. Nevertheless there is valid picture being presented by the parents interviewed of their experience of the loss of a child.

Finkbeiner (1996), on interviewing parents after several years of loss, said that on the surface one might think these parents to be depressed. The fact that they can't be bothered to dredge up enthusiasm, they don't have deep, sensitive feelings any more, their hearts just are not in it, they have a real so-what attitude about death, and that they would not be upset about dying, would be diagnosed depressive. Yet Finkbeiner found that the parents equally did not seem helpless or hopeless. In fact the parents could talk about these depressing thoughts almost light-heartedly, as though a lesser investment in life were almost a relief. Finkbeiner also recorded a new perspective within the parent's attitude. There was a change in priorities and values of life. It is not that after ten years, the child is always in the parent's thoughts, but rather that the death has caused an alteration in every thought within the parent. One parent expressed it as if life had been started over again, the zero point was the death of the child, from now on everything looked different.

Much of what has been said can be related to Knapp's (1986) findings. He found that parents who suffered the loss of an older child had shown emotions, feelings, and thoughts surrounding the loss which persisted in some cases for as long as twenty years, with no relief of the feeling in sight. The author's research along with Finkbeiner's seem to back up Knapp's conclusions at least for those associated with

‘Compassionate Friends.’ Yet it must be recognised that Finkbeiner and Knapp’s work also suffer from a biased sample base and a lack of any longitudinal study.

AN OVERVIEW OF THE LOSS OF A CHILD

The first reaction to the loss of a child seems to be one of shock from which the bereaved recuperates gradually. When the bereaved parent’s initial feelings of numbness begin to disappear and they gather themselves together, they often respond with ‘no, it cannot be true.’ Kubler-Ross(1983) suggests that in our unconscious mind we are all immortal. It is almost inconceivable for us to acknowledge that we too have to face death. Despite the shock, parents find that the moments of discovery remain engraved on their memories.

“I can remember every minute of the first two hours after hearing of his death”
(a mother, five years after the loss of her son, Merrington, 1996, p.50)

For some parents this was actually a moment of release as they see their child finally escape from further operations, drugs pain, and suffering.

“It was the first time I felt release since my child had become ill, twelve months previously. However later I felt guilty I felt like this” (a mother bereaved of a 8 year old girl, Merrington, 1996, p.50).

“For six weeks I sat with my son holding his hand while he was on the life support machine. I talked and talked to Paul, so that when it came to

switching off the machine, I felt ready” (a mother after the loss of a teenager, Merrington,1996, p.50).

When illness had been prolonged there was usually the opportunity to be with the child at the point of death. For some parents this was so painful that they wanted to escape. However, most found it a comfort to be with their child in the final minutes.

“I felt I couldn’t hold my baby, yet I also felt I had to. I was terrified of it.”

“I just sat and held him for an hour,” (Merrington,1995, p.50).

Most of the bereaved people expressed feelings of anger, rage envy and resentment at some time in the weeks after the loss, however for some there is a high degree of anger at the time of death.

“I was told not to talk about the death to other mums in the ward.”

A nurse gave me a glass of sherry, but it wasn’t a celebration.”

“I had sat up for nights with my child. The doctor encouraged me to go and get some sleep as he felt my daughter would last for days. Two hours later she died! I felt so cross with the Doctor” (Merrington,1995, p.50).

For many of the younger parents it is also their first experience of death within their family. There are also the events which take place immediately after the death that parents are just not prepared to encounter. The nurse taking a photograph of the dead baby, the doctor telling the parents that the child would need a post mortem, or the

police arriving at the door after a cot death. All of these situations can cause angry reactions within the parent. Slowly the reality of death dawns upon the parent as they begin to say to themselves, ‘Yes, it has happened, but why my child? Why me? Why now?’

THE DAYS FOLLOWING DEATH

For the first few days, as relatives and friends gather around, parents are in a daze. They experience a concoction of emotions. Relatives and friends find themselves just as helpless as they try to adjust to their own grief.

“One of our friends, from the moment of Carl’s death, has never been able to speak his name since” (Merrington, 1995, p.52)

It is as if parents awake each morning expecting a clear blue sky only to find darkness prevailing for them and their relatives and friends. It is while parents are in the thick of the fog that decisions have to be made. Registering the death (as well as the birth in some cases) can be exhausting. Trying to make decisions about the funeral when you are still trying to put together the events of the past days adds more pressure and tension. However helpful the funeral director or clergyman may be, it can still seem like an intrusion on a private affair. As friends and relatives come and go from the home, the family can feel in a state of limbo, between the death and the funeral.

One source of comfort is the flowers and particularly the cards that the family receive. The kind words expressed in simple terms mean a great deal at such a time. It is also a time for parents losing older children to discover more about their child from the deceased's friends. Other worries can pervade the mind of the bereaved parents. They may be worried about the other siblings, the cost of the funeral, the question of whether you should take sleeping pills, or what you should do with all the child's possessions. There is also the frustration of seeing the world continue to rush by as if nothing significant has taken place.

“Suddenly in the middle of a supermarket I wanted to cry and shout out,”
Stop, don't you realise I've lost my son”(a mother bereaved of a teenaged son, Merrington, 1995, p.73).

After the funeral, when relatives have returned to their homes and friends have gone back to work, parents are left with the cold reality that life will never be the same again. Some may enter a form of bargaining in their mind with God, wishing that their experience was nothing but a dream. However each day is the same grief filled experience as the parent carries real physical pain within themselves. Little things become so hard to carry out as the parent thinks far more about their child now dead than they did when alive. The emotions of anger, despair and guilt may well up at any moment in their grief experience. They may even have a few good days only to be engulfed with grief again. One parent the author interviewed scraped all the

wallpaper off the walls in her home, while another suddenly broke every plant pot in the house.

THE FIRST FEW MONTHS

Although many in society assume that the bereaved should be getting on with their lives months after a death, in fact for most, the situation seems to get worse, not better. There is a physical pain that remains along with the mental strain of constantly thinking about the deceased child. The parent's lives are in a state of disorganisation as siblings, the home, work and friends are neglected. The impact on siblings seems immense, as they have not only lost a brother or sister but now their parents are lost in grief. Many parents can find themselves sitting for hours in the child's bedroom surrounded with memories, belongings and smells. A voice that sounds similar to the deceased, a piece of music, or someone who looks similar can suddenly cause the parent to burst into tears.

“I just kept on crying and I didn't want to stop in fear of losing my son and all my memories” (mother one year after the death of her 21 year old son, Merrington, 1995, p.75).

THE FIRST YEAR

As the months go by parents find the evenings, particularly in winter, the worst.

Somehow they feel trapped in the home with all of their memories with no escape or

outlet. Eventually they reach the day they've been dreading, a birthday, a Christmas, a holiday or the anniversary of the child's death. At such times most parents simply want to hide away until the day is past. Others find ways of coping with such days.

“I would buy my deceased child a present first and only then would I be able to get on with my Christmas shopping” (Merrington, 1995, p.76).

For others such times are simply too much to bear.

“I hate birthday parties and holidays. They are the very time when the person who you would love the most is missing. I just wanted to die in the first year. Breast cancer, anything just to be with my son” (a mother who lost her nineteen year old son through suicide, Merrington, 1996, p.58).

Suicide was in fact a common thought on a parent's minds, particularly where an older child has died. In younger families although the pain is still present, there is the possibility of having another child. However, in older families all seems lost for the past and the future. Mothers particularly feel that there is no hope, no way of satisfying or fulfilling their lives and no purpose in continuing on without their deceased child. There is also the desire to escape the physical pain within.

Fortunately almost all parents do not commit suicide but it is an understandable reaction and reveals the depth of despair and depression they experience. The outcome is that parents end up with a lack of fear of their own death coming to terms with one's own mortality.

THE SECOND YEAR

By the end of the first year parents had expected that life would improve. However, the author found that the majority of parents felt that the second year was no better than the first year, in fact for some it seemed that the situation had worsened. This supports Rando's findings that grief intensifies over time (Rando,1983). By the second year, parents feel more removed from the events of the past year and therefore more separated from the dead child. On top of this people around them appear to have forgotten the deceased child and rarely mention the child's name. People are also expecting the parents to be becoming more sociable and back to their normal selves. However the parents see the situation very differently. For them the bubble of life has burst. The marriage and family life may be more tense, the husband may be under pressure from poor performance at work, and the court case linked with the death may have now happened (Stroebe,1998). There seems little to look forward to. On top of this, parents see other people survive similar accidents and illness and they observe the child's contemporaries continuing to grow and develop in life.

For parents who have lost babies and young children, they have to decide whether to start again, and if they do, how they will cope with their fears for their child's future. Parents who have lost teenagers and older children have to cope with contemporaries getting jobs, degrees and even being invited to their weddings. For some this period of loss is simply too much, the fact of death is so all consuming, the bereaved are

obsessed by it. The battle within gives way to breakdown and illness. For others the routine of work gets them through each day until they find themselves beginning to at least have some good days. However all the parents that the author spoke to acknowledged thinking about their child every day.

“You begin to learn that you will have good and bad days, you can’t predict which they will be, but at least you learn that, like the weather, there will be continual change” (a father who had lost a 23 year old son ten years ago, Merrington, 1996, p.59).

FIVE YEARS ON

Society may think that the bereaved ought to be back to a normal lifestyle after five years. In fact, it was found that parents were still grappling with their grief. There seem to be several factors at play here. Society around the bereaved has usually forgotten the events or consider them as past and gone (Stroebe and Schut, 1996). Parents will often hear the words, ‘you need to put it behind you now.’ However that’s just what older parents do not want to do.

“They think I can press an erase button and all my memories will be gone” (Merrington, 1995, p61).

Many parents make silent vows never to forget. The shadow grief that remains seems to be a cost of their love and commitment to the child and his or her memory. There is also the disturbing effect that as time goes on and as memories get distant in time, it creates a guilt reaction in parents. By trying to get on with life parents can push memories to the back of their mind, when it surfaces it can often seem muddled. This is a disturbing experience as parents endeavour to hold on to each event clearly. As parents find it increasingly more difficult to find people willing to listen five years on, they are unable to let their thoughts be released and so they carry an inner frustration. Other accidents and illnesses that occur in society, which are similar to the deceased's story jar the memory of parents. There is often a sense of anger and disappointment when they involve accidents, particularly as parents feel society has not learned the lessons of the past. Bereaved parents continue to see all around them their dead child's contemporaries getting on with life. However pleased they may feel for them, it is also painful to acknowledge.

Other difficulties parents face lie much closer to home. If they have younger children, then there is the worry that they too may die at the same age as their deceased brother or sister. If they have older children, then by now they may well have left home, creating a void in the parent's lives.

The following vignette illustrates the way that the loss of a teenager influences a family.

Sally was the boss of the family. She had just celebrated her seventeenth birthday with an enormous party. The home had been full of excited teenagers bursting with energy. Sally was the sort of girl that always had friends around her. She was doing well at school with her A levels... the sort of girl that set a good example in school. That's not to say everything was plain sailing in her life. Her strong-willed character created a few frictions in her home with her parents, John and Mary. Sally had got herself hooked on diets. As soon as she finished one diet, she would start another. Not far from the edge of anorexia, if it had not been for the support of her parents and Sally's determination, she might well not have recovered. But now her confidence was restored and she was back to the usual tussles with her older brother and disagreements with mum and dad. The main argument one weekend was her boyfriend. Dad was not keen on him, which only pushed Sally closer to Ian. Mum would encourage Sally to spend time with her in the kitchen baking cakes as an opportunity to get underneath this fiery character and find out what Sally really felt. One night her boyfriend rang, wanting to take her out with her friends. Dad immediately said no, but Mum - feeling Sally was under pressure - said yes, provided it was for a quick hour. As they left in the boyfriend's car, the atmosphere was tense between Mum and Dad. Several hours passed and Sally still hadn't returned home. The parents went to bed, but were only half sleeping when Mum suddenly woke up with a start. She hesitantly went into Sally's secret domain, her bedroom, and for the first time ever opened her daughters diary to find telephone numbers of her friends

to ring. No one seemed to know where Sally had got to. Minutes later the Police arrived. The three teenagers had given a lift to a friend and were on their way home, when their car collided head on with a taxi which was on the wrong side of the road. Three people were killed. The boyfriend and the taxi driver survived.

It was a small town but the church was overflowing for the funeral. Everyone seemed to want to share in the parents' grief. However as time went by, they found themselves feeling isolated. Several friends kept away altogether after the funeral. It was as if Sally had never existed. Friends would ask after the son, but not mention Sally's name, while others would come out with painful comments, which Mary vividly recalled," They'd tell me about the accident they had, or encourage me to let my daughter go, as if I could forget her. One friend suggested that her divorce had been much worse !"

Sally's grandparents and relatives too found it difficult. John's father had been ill before Sally's death; once his granddaughter had died he seemed to give up the fight. Mary's brother lived in the north of Scotland so didn't come to the funeral and this created tense feelings in the family. Nevertheless, good things did result. Sally's father recalled how he had lost his sister in a car accident when he was a child and now began to understand better his parents' reaction over the years. Sally's grandmother suddenly started to visit her granddaughter's grave and began to talk about her in a new way. Amazingly, the grandmother had also lost her sister in a

bicycle accident as a child. Some of Sally's friends would visit and share with the parents' stories about their daughter they had never heard. It was a great comfort to Sally's mother to know what a fine girl their daughter had been. Soon the family acquired a cat; Sally had always wanted one. Around the house were pictures of Sally.

Five years had passed, and Sally's brother had moved away from the house. He found life with his grieving parents rather claustrophobic. John and Mary acknowledge that they had gone through ups and downs in their marriage but were at least still together. Work was far less important to them now. They had acquired a simple attitude of living day by day. The contact with Sally's friends had dwindled, which saddened them. They still felt a strong sense of anger. Anger to the taxi driver, at the boyfriend, at God, at Sally, and at themselves for all the mistakes they felt they had made.

"The most upsetting thing is when people deny reality; they think we're contagious so they keep away. We've lost not only growing up with her, her exams, marriage, children, but most of all we've lost a friend, our best friend who influenced us for good."

Sally's story was typical of the events that followed a teenager's death.

TEN YEARS ON

By now, the author found that parents had realised that although they may be coming to terms with their loss, they would never get over it.

“If final acceptance is getting over it, then I never will. But if acceptance is missing him, then I am there now.” (a mother bereaved of a teenaged son, p.80).

“I still have off days, especially when I see mums with children the same age as my child.” (a bereaved mother who had lost a nine year old girl).

“When someone comes up to you and asks, ‘How’s your daughter?’ it’s like a dagger turning in me.” (a bereaved father who had lost a teenaged daughter, p.80).

“I still avoid pregnant women.” (a mother who had lost a baby at birth. p.80).

“You can come to terms with it, but you never get over it.” (a mother who had lost a twenty year old son. p.80)

It seems that parents continue to remember their child. Some parents hold on to the picture that they had of their child at death, while others image their child aging and developing over time. When parents have lost older children who already had children of their own, there seems to be an additional complexity of relating to grandchildren. The wife or husband in-law may have remarried and prefer the grandparents not to talk about the deceased.

Yet the bereaved parents may be desperately wanting to share with their grandchildren what their father or mother had been like.

In the next chapter there is an investigation of grief in a non-western culture.

CHAPTER 6

INVESTIGATION OF GRIEF IN NON-WESTERN CULTURES

INTRODUCTION TO THE AFRICAN STUDIES

This chapter describes an investigation of grief in a non-western culture, attempting to clarify whether shadow grief was present in differing cultures.

Having carried out a brief study of bereaved parents in Beirut, Lebanon (appendix 8); a fuller procedure was carried out in Africa focusing upon three localities in Uganda and Tanzania. The first was a remote rural location in the foothills of the Rwenzori Mountains on the edge of the Zaire - Uganda border (figure 5 & 6). The second was a town in the foothills of Kilimanjaro in Tanzania (figure 7). The third location was a remote Kraal community living on the plains of Kilimanjaro on the borders of Tanzania and Kenya. The three locations were chosen because they reflected a diversity between communities while still exhibiting a high degree of child loss. The exact locations were chosen because of personal contact with the communities involved.

1) KAGANDO HOSPITAL, KASESE DISTRICT, UGANDO

Uganda is a land locked nation lying astride the equator more than 2000 Km from the nearest ocean. It is predominantly an elevated basin with one sixth consisting of lakes, rivers and marshes.

Uganda has more than forty clearly distinct ethnic groupings. Half of the population consist of the Bantu tribe. It is a country in which large populations have migrated because of war and civil unrest. There is also a significant number of migrants from other countries such as Sudan because of conflict in their own countries. Death is not uncommon. Between 1962 -1986 national leadership changed hands seven times. Hundreds of thousands died in army conflicts. The population is getting younger, compared to a 1950 profile, the proportion of children and youth in the total population has almost quadrupled. Uganda was one of the first African nations to acknowledge AIDS. Nearly 80% of those affected with HIV are in the economically productive and reproductively active ages between fifteen and forty five.

The first set of interviews carried out were based around the Kagando Hospital community in the Kesese district of Uganda. This location was chosen because it represented a rural community which still maintained many of its local traditions. The majority of inhabitants lived off the land living in simple homes made of clay and straw. Being on the edge of the Equator, the weather and soil conditions allowed the people to survive without any obvious signs of malnutrition. However at the time of interviewing, rebel activity within the Rwenzori Mountains created an atmosphere of fear and uncertainty.

FIGURE 5 UGANDA

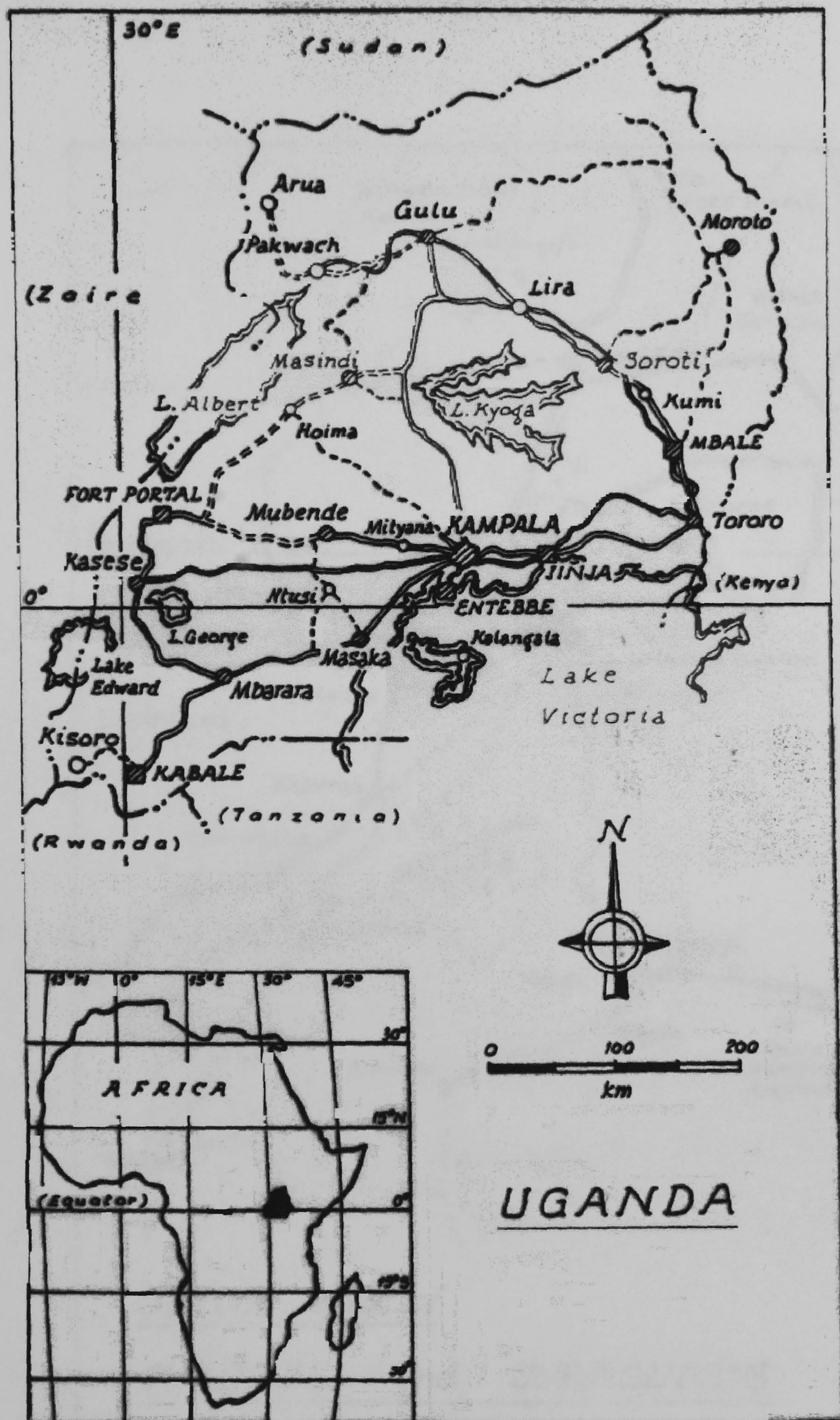


FIGURE 6

KASESE

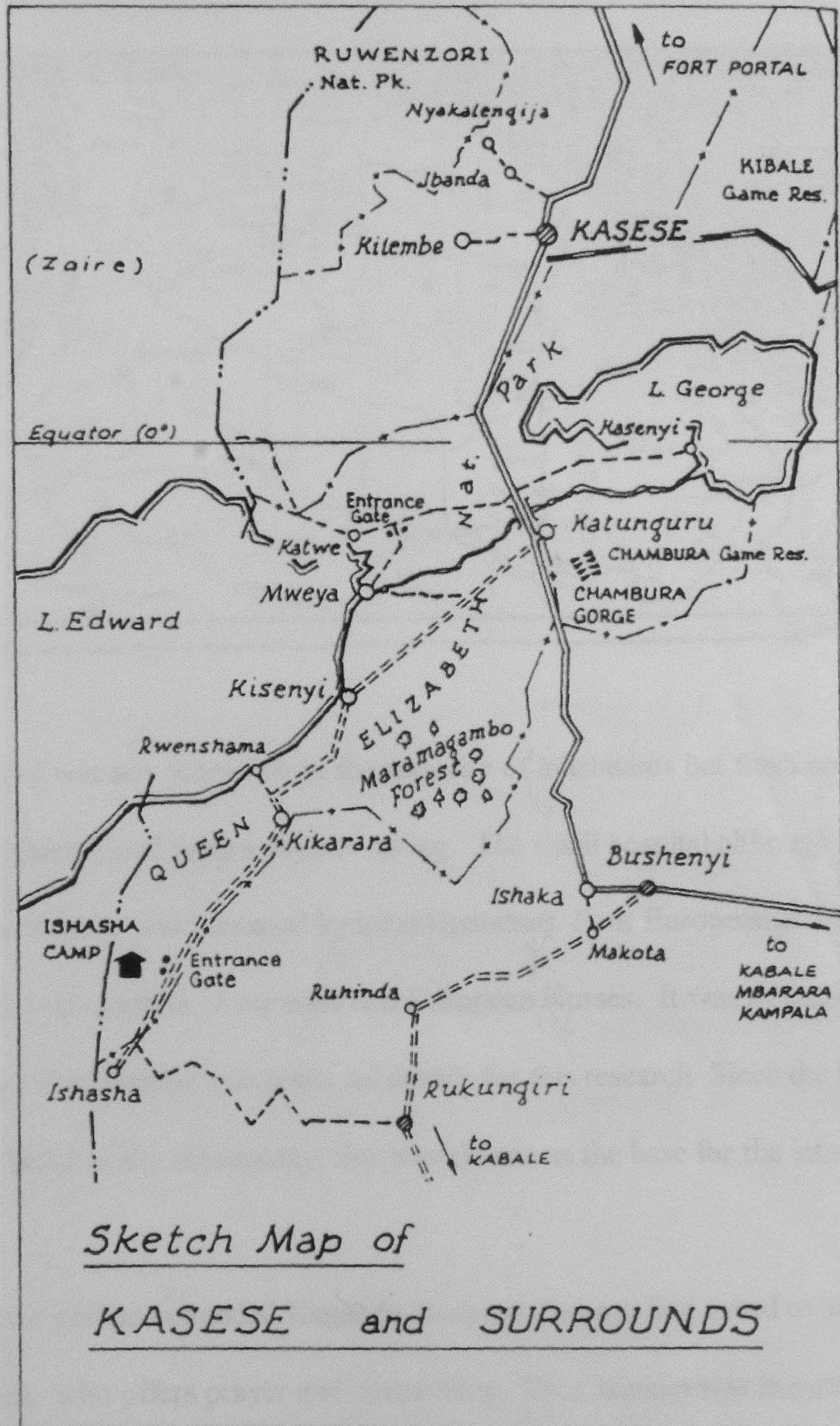
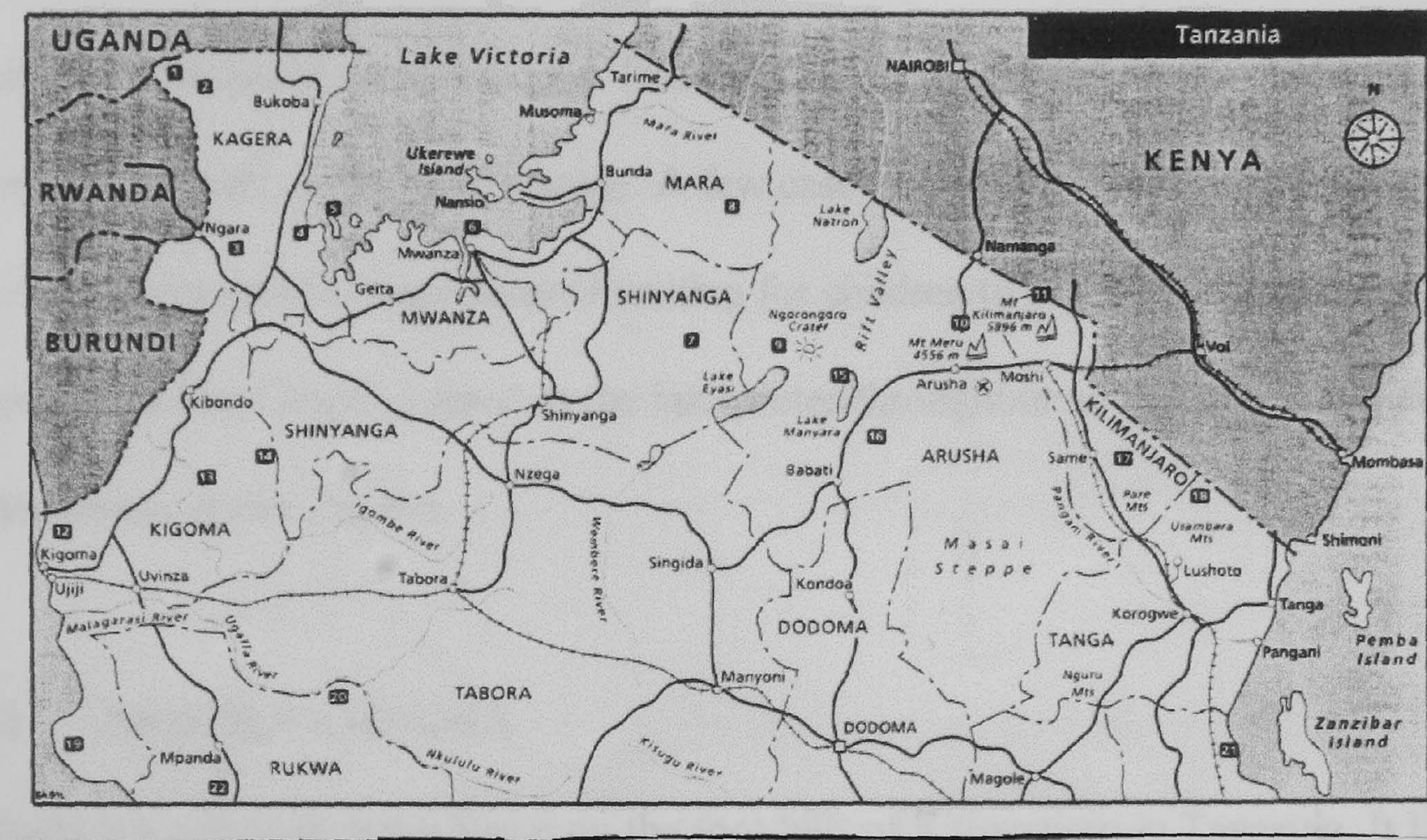


FIGURE 7
MOSHI, TANZANIA



Electricity was not accessible to the majority of inhabitants but fresh clean water had recently been piped from a capped spring. The small hospital although supported by western finance, was managed by local Ugandans. Four European and American Doctors were present along with two European Nurses. It was through the European presence that contact was made accessible for this research. Since the hospital was a central point to the community, this was chosen as the base for the interviews.

Whenever patients attended Kagando Hospital they are first asked to see the Christian Chaplain, who offers prayer and counselling. The Chaplain was therefore used as a means of contacting the bereaved. All participants were simply asked by the Chaplain

whether they would be willing to be interviewed with no pressure or obligation. The majority of interviews took place within an office attached to the Hospital. Patients in the Hospital are required to bring a helper to both assist in nursing and to provide food for the patient. It was from these helpers, along with those who lived locally, that the participants were obtained. In some cases the interviews took place out in the community in the participant's home. A few cases were interviewed in temporary homes where families were housed waiting for children to recover from club foot operations. The Chaplain acted as the interpreter throughout all the interviews as no interviewee spoke English.

2) MOSHI, TANZANIA

Moshi is a relatively large Town on the foot hills of Kilimanjaro in Tanzania. It lies between Kilimanjaro Airport and Arusha which leads to the Safari parks of the Ngorongoro and Serengeti. Therefore, although only a few tourists actually stop here, as a town it has developed commercially compared to the majority of Tanzania. The locality is also fortunate in having a rather wet climate compared to the southern part of the country and is very fertile. This location therefore represented a more developed location as compared to Kagando. The town had one of the best hospitals within Tanzania.

In Moshi the participants for the interviews were obtained via contacts with the Anglican Church of Tanzania. Interviews took place in the town and in the compound

of a sugar plantation 30 kilometres out of town. In each interview a retired Pastor translated and initiated the introduction. He also pastorally cared for the participants afterwards. Only one interview was carried out fully in English and in this context no translator was present. All the other interviews took place using the Swahili language.

3) MASAI PLAINS, KILIMANJARO, TANZANIA

The third set of interviews took place in a remote Kraal community, on the plains of Kilimanjaro. To reach this community from Moshi, a one hour journey in a Land Rover, followed by a three hour walk into the bush was required.

The Masai are a tribe spread over 30,000 square miles of Tanzania and Kenya. There are an estimated 60-70,000 Masai living a semi-nomadical life in remote and scattered cattle kraals.

Access to the Masai is difficult as they are a community that chooses to be withdrawn and remote from other civilisations. Normally, contact with westerners is made by receiving gifts in exchange for photographs etc. Access to one Kraal community was achieved by an educated Masai Doctor who had returned to his people to minister amongst them. This doctor acted as a negotiator and as the interpreter throughout the interviews.

The Masai were chosen to be interviewed due to their unique independence from the rest of the society around them. The aim was to observe whether their experience and understanding of child loss was different from more westernised communities.

These three communities were studied so that a contrast could be made between the loss of a child in a child-centred western community as compared to communities where the death of children is common. Three hypotheses were tested.

1. Whether there were long term effects of grief upon parents who had been bereaved of children. It was predicted that if parents had formed strong affectionate bonds with the child then there would be some sign of shadow grief present irrespective of the high level of child mortality in the African communities and other differences from the United Kingdom.
2. Whether the age of the child at death had an impact upon the parent. It was predicted that as in the English data, parents would show increased bonding to a child with age and would therefore show increased signs of grief factors.
3. Since rural close knit communities in England were found to be better equipped to show ongoing support to the bereaved, one would expect to see a similar pattern in these rural communities with perhaps a slight difference in the town data of Moshi.

If shadow grief was found to be present regardless of the type of community the loss took place in, then this would allow an evaluation as to whether shadow grief could

be identified in a variety of settings. These three communities provided a contrast with the English setting while at the same time providing an opportunity to observe the differences between closed, rural and town communities.

FACTORS IN COMMON

There are a number of factors in common between the three communities which allow for a comparison to be made with the English data previously gathered.

URBANISATION

Uganda and Tanzania represent countries which are extremely unurbanised. Almost ninety percent of the population live in rural areas. This is in sharp contrast to the population distribution in England.

FERTILITY

About half of the populations of Tanzania and Uganda are under the age of fifteen years old. Along with this is a low access to family planning services (Barton, 1994).

TABLE 22

FERTILITY OF WOMEN IN UGANDA (BARTON,1994)

AGE OF WOMEN	% OF WOMEN THAT GIVE BIRTH TO THEIR FIRST CHILD AT A SPECIFIC AGE
UNDER 15YR	10 %
15-17YR	43 %
18-19YR	24%
20-21YR	13 %
22-24YR	6%
OVER 25YR	4%

The consequence of this is a very high fertility rate among teenagers aged between 15 and 17 years (table 22). This inevitably leads to families with large numbers of children.

TABLE 23

AVERAGE FERTILITY RATE PER WOMEN’S LIFE TIME (BARTON,1994)

LOCATION	TOTAL FERTILITY RATE
TANZANIA	6-7 CHILDREN
UGANDA -GENERAL	7 CHILDREN
UGANDA - KASESE DISTRICT	8 CHILDREN

One of the research sites however has a slightly higher rate of fertility (Table 23). In the Kesese district of Uganda where Kagando is located, there seems to be a larger percentage of women giving birth. The reason for this may be its greater remoteness and the lack of general medical support within the district. It generally appears that the fertility rate reduces as the community becomes more influenced by the west. In

an area where death rates for infants are high, it is more beneficial to have a larger number of children. Children play a key role in the welfare of a family. They are able to help with the crops and the rearing of animals. If your existence is by living off the land, it is important to one’s survival to have enough help.

MORTALITY

The mortality rate within the two countries of investigation has generally been high (table 24), however the affects of AIDS is causing this rate to increase considerably.

TABLE 24
LIFE EXPECTANCY (BARTON,1994)

COUNTRY	LIFE EXPECTANCY - AGE
TANZANIA	50 YEARS
UGANDA	40-45 YEARS

It is expected that the life expectancy for 2001 in Uganda will drop below 40 years of age due to the spread of AIDS. Although AIDS can be found in most African countries, its impact varies considerably. In Tanzania it is believed that 200-400 people per million are affected compared to 400-600 in Uganda. However in the Kasese district of Uganda where the interviews took place, the AIDS rate was recorded as between 1000-2000 per million. However local Doctors suspect that

actual figures may be higher by five times these figures. The impact of AIDS in the Kasese district upon the local community is considerable.

It can be seen from Table 25 that it is not just AIDS that causes the death rate to be so high. However in the remote parts of Tanzania and Uganda it is difficult to obtain accurate reasons for death. This is particularly true for AIDS where there may be a reluctance to acknowledge this as the cause of death.

TABLE 25
CAUSE OF DEATH IN UGANDA AND TANZANIA (BARTON,1994)

	CAUSE OF DEATH IN UNDER FIVE'S IN TANZANIA (%)	CAUSE OF DEATH IN UNDER FIVE'S IN UGANDA (%)
MALARIA	25	21
DIARRHOEA	20	8
NEONATAL	15	-
MEASLES	8	10
PNEUMONIA	21	8
NEONATAL PNEUMONIA	6	-
HIV AIDS	-	5
OTHER	5	48

DIFFERENCES BETWEEN THE AFRICAN LOCATIONS

Each of the three locations had its own unique features which gave a contrast to the analysis.

KAGANDO, UGANDA

This area was special because of its remoteness. Although western Doctors and Nurses were present in small numbers, their influence on the life style of the people was small. Although there had been influence by western Christian concepts, the majority who were interviewed portrayed more local beliefs. For example, the role of the hospital was seen as no more significant than the local witch doctor or the understanding of the 'living dead' concept. A second note worthy factor for Kagando was that of the increased deaths caused by random killing. The local rebel action had increased the awareness of death within the community.

MOSHI, TANZANIA

Moshi represented a more typical African Town in Tanzania. Here there was a greater degree of education along with more western influences. The impact of Christianity was particularly more relevant especially since the interviewees mainly came from the links of the local Church.

MASAI PLAINS, KILIMANJARO, TANZANIA

The Masai are a unique nomadic community who are difficult to get close to. They have their own form of language although some speak Swahili. In their native language there is no future tense, tomorrow will be like today. Although they live in the foothills of one of the world's most beautiful mountains, they had no inclination to

want to climb it. The highlight of each day was to sit at night amongst the animals within a closed pen, the men chatting between themselves whilst the women would be in the dark Kraals preparing a milky drink.

On the surface the Masai would appear to have few religious beliefs. However they were believers of one God called Engai, but were also plagued with fears of evil spirits. There seemed to be little belief in immortality. When a person died, they were simply left at the edge of the village for the Hyenas to consume. Normally death is not a subject that the Masai would readily talk about to a stranger. Care had to be taken by the Masai interpreter in not offending the participant. Customs of sitting together, drinking milk or char, and entering their 'bomas' were necessary before one could raise the issue of an interview. Even then the Masai were generally suspicious as to why one would carry out research since this kind of concept was alien to them. There was also the question of, 'what difference would it make if I shared myself with you?' The Masai did not believe in the concept of the individual but rather a collective view and opinion of the whole community. Therefore the idea of interviews individually seemed unnecessary to the community leader, as there should be only one collective view and answer to any question. However despite the difficulties, three interviews did take place including the community leader who had also lost a child.

METHOD

The design of the research was shaped with the desire to contribute further knowledge to this field and to be informative to clinical counsellors who care for

bereaved families. The study used an interview technique previously used in earlier research. It was decided not to incorporate either the Grief Experience Inventory or the Parental Interrelationship Questionnaire due to the complexity of cross cultural communication. From previous experience in interviewing bereaved parents in Beirut, Lebanon, it was clear that any interview technique had to be simple, keeping areas of misunderstanding to a minimum.

GENERAL PROCEDURE

Based upon previous research in England, a basic interview schedule was produced which contained the major areas of interest (Merrington, 1995). The topics addressed in the structured interview focused on the parental loss of children. The format was designed to assist the parents in describing their experiences from the time of their child's diagnosis to the period of readjustment subsequent to the death. The questions were designed to be open ended as far as possible to encourage the parent to express in their own words their experience.

After obtaining basic factual information, the interview schedule focused upon the following areas: the process of death and support at the point of death; reaction during the first few days of bereavement; the family and community reaction; the effect of loss upon the parents at the time of interviewing and the hope and belief rationale within the parent. Once completed, the interview schedule was translated into Swahili for interviews in Tanzania and then translated back to English to see if

there were any areas of miscommunication (appendix 9). Adjustments were made before the final interview schedule was taken to Africa.

Role play with two interpreters was carried out to identify any areas of misunderstanding of the interview schedule. This took place in Uganda and Tanzania. Also after the initial three interviews in Uganda the questions were adjusted to simplify the process thus further reducing any possibility of confusion in the participant (table 26). It had been hoped to record all the interviews but it became obvious that this was inappropriate as the majority of parents had not seen a tape recorder and it therefore proved to be both a distraction and inhibited the participant in responding to questions.

When an interview was initiated, the interpreter clarified to the participant that the aim of the interview was to aid research and understanding of bereavement thus assisting bereaved people both in England and in Africa. It was made clear that there would be no payment for the interview. However as a sign of thankfulness and due to the shortage of food, a gift of a bag of rice or sugar was given to the participant a few days later. Being aware of the personal nature and emotional reaction that such an interview produces, care was taken to give participants time to answer in their own way. There was also a conscious effort in making sure that the interview ended on a positive creative note. The interpreter took on the task of being responsible in continuing the link with the bereaved in the days that followed interviewing. On the

whole the interview took no longer than anticipated, averaging one to one and a half hours.

TABLE 26

INITIAL DESIGN OF SHADOW GRIEF BONDING INTERVIEW SCHEDULE
BEFORE GOING TO AFRICA (MAY 1997)

1. Name	M/F						1 2	
2. Age	10-20	21-30	31-40	41-51	51+	1 2 3 4 5		
3. State	Single	Partner	Multi-partner	Widow	1 2 3 4			
4. Number of children alive	0	1	2-3	4-6	7-10	11+	1 2 3 4 5 6	
5. Name of deceased child/children								
6. Child's age at death	prenatal	0-2	3-10	11-17	18+	1 2 3 4 5		
7. Time since child died		0-2	3-5	6-10	10-15	16+	1 2 3 4 5	
8. When did you name your child before birth	at bith	<6mth	>6mth	1 2 3 4				
9. Who named the child	par	/	rel	/	oth	1 2 3		
10. Type of death	illness	accident	murder	suicide	1 2 3 4			
11. Process of death	sudden	24hrs	1-7days	7days+	1 2 3 4			
12. How many children born since death	0	1-2	3-5	6+	1 2 3 4			
13. What is the closest relative that has died since								
14. How did they die								

ANTICIPATION

15. Who spent the most time with the child just before death

16. What problems had you experienced before death (war, illness, food)		1 2 3 4
17. Did you ever expect to lose a child	y / n /?	1 2 3
18. Did you sense this child would die	y / n	1 2
19. Was there medical help	y / n	1 2
20. What kind of family help	y / n	1 2
21. How did you feel about your child dying angry, alone numb, sad , ?		1 2 3 4 5
22. Did you prepare what you would do at death	y / n /?	1 2 3
23. Did you bring in a religious leader	y / n	1 2
24. Were you present at death	y / n	1 2
25. Were you alone or with others	y / n	1 2
26. Did you hold your dead child	y / n	1 2
27. How long did you stay with your child	min hrs days	1 2 3
28. How did you react at the death	shock numb calm	1 2 3
29. Who helped at the time of death	none/ fam/ friend/ comm.	1 2 3 4
30. Who helped with the funeral	none/ fam/ friend/ comm.	1 2 3 4
31. What kind of ceremony did you have		
32. What in the funeral helped you	min/peop/ rite/?	1 2 3 4
33. Could you afford the ceremony you wanted	y / n	1 2
34. Did you want people to see the dead child	y / n	1 2
35. What did people say to you		

FIRST MONTH

36. Was it difficult to a. fall asleep, b. stay asleep, c.wake early		1 2 3
37. Did you feel tired	y / n	1 2
38. Did you feel any physical pains	y / n	1 2
39. Did you feel suicidal	y / n	1 2
40. How much did your family help	none/little/ lot	1 2 3
41. How much did the community help	none/little/ lot	1 2 3
42. How did the religious leaders help	none/ little / lot	1 2 3
43. Whose fault was the death	God / spirit / world / none	1 2 3 4
44. Whose fault was the death	self / relative / none	1 2 3 4
<u>AFTER THE FIRST YEAR</u>		
45. How was your health	good / poor / normal	1 2 3
46. How much did you think about your child	none / little / lot / all	1 2 3 4
47. How did birth.anniv, fest.s affect you	none / little / lot	1 2 3
48. How did it affect your feelings		
49. Did you feel physically aggressive	y/n	1 2
50. Could you control your sadness	y/n	1 2
51. What was the hardest time in the first year		
52. Did you think about your own death	y/n	1 2
53. Did you sense your child's presence	y/n	1 2
54. Did you talk to your deceased child	y/n	1 2
55. How did you feel about your other children	>protective / <protective / same	1 2 3
56. Who supported you the most in the first year	family /friend / community	1 2 3
57. After the first year did you feel better	y/ n / same	1 2 3

58. How did the loss affect you		
59. Did you fear others might die	y / n	1 2
60. Did you change your behaviour with other children	y / n	1 2
61. Does it still affect you	y / n	1 2
62. How much do you still think about your child	non / little / lot / all	1 2 3 4
63. Did you want more children	y / n	1 2
64. Has another child replaced the one you lost	y / n	1 2
65. Has it affected your health today	y / n	1 2
66. Has it affected your relationship with your family	y / n	1 2
67. Has it affected your relationship with the community	y / n	1 2
68. Do you still talk to your child	y / n	1 2
69. Do you still have possessions of the child	y / n	1 2
70. Has your view of God changed	y / n / inc / dece	1 2 3 4
71. What are the main problems that you have today		
72. Are you able to cope with your loss	y / n	1 2
73. Who do you blame for your loss		
74. Can you still be sad	y / n	1 2
75. Do you think about where your child is now	y / n	1 2
76. Do you long for the child to be with you now	y / n	1 2
77. Do you feel suicidal	y / n	1 2
78. Do people talk about the child	y / n	1 2
79. Would you like people to speak about your child	y / n	1 2

80. Do people avoid you because of your loss	y / n	1 2
81. Does it help that others around you have also had loss	y / n	1 2
82. How do you feel when you see children at the age when your child died		
	ok / sad / pos	1 2 3
83. How do you feel when you see children who are at the same age your child would be today		
	ok / sad / pos	1 2 3
84. Do you go to funerals of children	y / n	1 2
85. Do you still have bad days	y / n	1 2
86. Where is your child now	heaven / here / ?	1 2 3
87. Can you picture him/her	y / n	1 2
88. What kind of God do you believe in		
89. Has any good things resulted because of the death	y / n	1 2
90. Has it affected your character	y / n	1 2
91. Have you changed your behaviour / attitude / way of thinking	y / n	1 2
92. What is your best memory of your child		
93. What one good thing has happened to you recently		

After initial assessment, the interview schedule was simplified to draw out a number of key questions (keeping to the numbering of the first questionnaire):

TABLE 26a

SIMPLIFIED VERSION OF INTERVIEW SCHEDULE

(Keeping to the numbering of the first schedule)

1. Sex
2. Age of parent
3. Marital status
4. Number of children alive
5. Number of children dead
6. Children's age at death
7. Time since death
10. Type of death
11. The process of death
12. Number of children born since loss
17. Did you expect to lose a child
19. Was there medical help
25. Were you alone at death
26. Did you hold your dead child
28. Did you cry/ weep at the point of death
29. Did you desire to be with company
34. Did you want people to see the deceased at the funeral
35. Were people helpful
39. Did you feel suicidal

- 43. Who did you blame for their death
- 47. What made you think about your child
- 49. Do you feel angry
- 53. Do you sense the presence of the child
- 54. Do you talk to the deceased
- 69. Do you have any possessions of the child
- 75. Do you visit the grave
- 81. Does the high number of deaths around you help
- 82. How do you react when you see other children around you the same age as the deceased child
- 86. Where is your child now
- 86B. Will you see your child again
- 94. Do you believe in the 'living dead'
- 95. How do you feel talking about this loss

FINDINGS

From the six week period interviewing in the three regions one hundred individual parents were interviewed in Kagando in Uganda and fifteen were interviewed in Moshi, Tanzania. Of those interviewed a high percentage were females (table 27).

TABLE 27

SEX OF INTERVIEWEES

SEX	MALE %	FEMALE %
Total	13	87
Uganda (n=100)	12	88
Tanzania (n=15)	20	80

In the Ugandan setting there was a greater ratio of women helping and supporting patients within the hospital as compared to men. However a larger proportion of men came forward in the Moshi, Tanzania setting. This was probably because of the more personal invitations which were made through the pastors of churches. In contrast in Kagando, Uganda, the invitation was a general one via the radio within the hospital. The pastor or interpreter therefore had less knowledge of the interviewees who came forward and was not in a position to invite men specifically. From the English data where 39% of the interviewees were men, it can be seen that men were less represented in the African sample. This reduced the ability to draw a clear comparison between the English and African data.

TABLE 28

ESTIMATED AGE OF INTERVIEWEES (YEARS)

AGE	10-19	20-29	30-39	40-49	50
Total %	3	20	23	22	32
Uganda % (n=100)	3	21	24	22	30
Tanzania % (n=15)	0	13	20	20	47

Although the interpreter was able to calculate the age from what the interviewee said (table 28), it was in fact very difficult to know whether these ages were correct. This was due to the fact that the majority of people interviewed did not know their birth day or the year that they were born. However about half of the interviewees were probably forty years plus.

TABLE 29

STATE OF RELATIONSHIP OF INTERVIEWEES

STATE	PARTNER	MULTIPLE	DIVORCED	WIDOW	SEPARATED
Total %	52	16	7	25	1
Uganda % (n==100)	52	18	6	24	0
Tanzania % (n=15)	53	0	7	33	7

An important difference between the English data and this African data is the large percentage of people interviewed in Africa who had multiple partners or had been widowed (table 29). The multiple partners were simultaneous rather than in succession. To have multiple partners reveals the complexity of relationships and the impact that loss might have upon such bonds. There is also the fact that over a quarter of people interviewed had been widowed themselves and were therefore well acquainted with grief. It was interesting to note that several parents who were divorced or separated attributed the death of their child as a contributing factor to the breakdown in the relationship.

TABLE 30

NUMBER OF CHILDREN STILL ALIVE

CHILDREN ALIVE	0	1-3	4-6	7-10	11-13
Total %	4	27	39	27	3
Uganda % (n=100)	5	25	38	29	3
Tanzania % (n=15)	0	40	47	13	0
	Mann-Whitney U =608.5, p = 0.237				

In the African data, 96% of the interviewees had surviving children, and 68% had four or more as compared to the English data where over 73% of parents still had living children but these consisted of families with only one or two children (table 30).

The difference between the two African samples was not significant.

TABLE 31

NUMBER OF CHILDREN DEAD

NUMBER OF CHILDREN DEAD	1	2	3	4-5	6-9
Total %	39	27	15	12	7
Uganda % (n=100)	34	30	15	14	7
Tanzania % (n=15)	73	7	13	0	7
	Mann-Whitney U =477.0, p = 0.018 Median Uganda = 2 Mean = 2.44 Tanzania = 1 Mean = 1.74				

In the English data only two parents had lost one or more children previously. In England, multiple losses related to premature deaths due to difficulties with pregnancy within the mother. The African data reveals a very different picture for bereaved parents (table 31). The difference between the two African samples was statistically significant. The Ugandan figures are particularly high for multiple loss with 66% interviewed experiencing the death of more than one child. In contrast, the figure for Tanzania was 27%. One might have thought that this difference was due to town life as compared to a rural one with parents choosing to give birth to a smaller number of children. However the figures in table 25 do not bear this out. It is more likely to be due to the fact that there is a higher mortality rate associated with the lower level of medical care in the rural parts of Kasese as compared to the town of Moshi. One might in fact see similar figures if one measured the number of deaths of children in a remote Tanzanian district. However this does not account for the high level of death rates for the death of the first child in Tanzania. Although there is no evidence to draw a conclusion, one reason may be due to the fact that parents are generally reluctant to have any association with hospitals initially. After the first death parents may decided to seek medical help thereafter. This would need to be tested in further research.

TABLE 32
CHILD'S AGE AT DEATH

CHILD'S AGE AT DEATH	PREMA TURE	0-2	3-5	6-10	11-15	16
Total %	1	43	19	11	6	20
Uganda % (n=100)	0	46	20	12	7	15
Tanzania % (n=15)	7	20	13	7	0	53
Mann-Whitney U = 525.0, p = 0.125						

There was a wide range in the age of the child at death (table 32) although the difference between the two samples proved not to be of statistical significance. Since parents had difficulties being accurate with their own age, it might be assumed that parents were also unclear of the exact age of the child at the death. However the younger mothers were able to be more specific. It was surprising that only a small number of parents interviewed had experienced the loss of a premature baby. This may reflect the thinking of the community that the death of a premature baby is not a significant loss rather like Nancy Scheper-Hughes' (1992) findings in the Brazilian shantytown . The data does show a large percentage of Tanzanian parents interviewed who had lost a child aged 16 years old or over. There was no clear reason why this percentage should be so high. One might have expected it if it had been in Uganda due to the high levels of killing.

TABLE 33

TIME SINCE DEATH

TIME SINCE DEATH	0-2 YEARS	3-5 YEARS	6-10 YEARS	11-15 YEARS	16+ YEARS
Total %	36	23	19	6	16
Uganda %(n=100)	36	23	19	7	15
Tanzania %(n=15)	33	27	20	0	20
Mann-Whitney U = 736.5, p = 0.910					

There was a large range in the number of years that had elapsed since the loss of a child (table 33). This was fortuitous in that it gave a realistic opportunity to be able to see whether the nature of grief depended on the time since loss. From the 115 interviews, 64% had been bereaved for at least three years, 22% over ten years and 16% of the parents bereaved over 16 years or more. The difference between the two samples was not statistically significant.

Questions 8 and 9, relating to the naming of the child and the role people had in the naming process, proved to be rather difficult to explain and gain relevant answers. Since this was not a significant area of research, these questions were left out of the majority of interviews.

TABLE 34

TYPE OF DEATH

TYPE OF DEATH	ILLNESS	ACCIDENT	MURDER	SUICIDE
Total %	90	4	5	1
Uganda % (n=100)	95	1	4	0
Tanzania % (n=15)	65	18	13	7
	chi-squared =16.43, df = 1, p< 0.001			

The large majority of interviews, especially in Uganda, involved parents whose child had died because of illness (table 34). In the English data, 60% of parents interviewed had had a child die from illness while 33% had died by accident. The Tanzanian data had a lower percentage of deaths from illness, but more deaths from murder and suicide. The differences between the two samples was statistically significant, chi-squared=16.43, df=1, p<0.001 (to avoid very small cell counts, accident, murder and suicide were combined into a single category). One reason for this could be the better facilities of health care in the town as compared to the remote countryside of the Ugandan situation.

TABLE 35

PROCESS OF DEATH

PROCESS OF DEATH	SUDDEN	24 HOURS	1-7 DAYS	7+ DAYS
Total %	20	5	49	26
Uganda % (n=100)	16	5	53	26
Tanzania % (n=15)	40	7	20	33
chi-squared = 7.17, df=3, p =0.067				

A breadth of data was obtained on whether the death of the child was sudden or whether there was time to begin to anticipate death and therefore begin grieving for the potential loss (table 35). However no obvious differences were observed between those who had knowledge of the forthcoming death as compared to those where death was sudden and unexpected. If there had been differences, it proved difficult to identify in the interview. It was also hard for parents to expect the death, even with information as to the seriousness of the illness or injury. One might have expected a difference if parents had been preparing for a death over weeks and months. The difference between the two samples was not statistically significant.

TABLE 36
CHILDREN BORN SINCE LOSS

CHILDREN BORN SINCE LOSS	NO CHILDREN	1-2 CHILDREN	3-5 CHILDREN	6+ CHILDREN
Total %	60	23	12	4
Uganda % (n=100)	55	26	14	5
Tanzania % (n=15)	93	7	0	0
chi-squared = 8.12, df =3, p = 0.044				

It is interesting to note that there were more children born after the loss of a child in Uganda as compared to Tanzania (table 36). The difference between the two samples was statistically significant. Since a high portion of those interviewed in Tanzania had in fact lost older children, it was not surprising that they had not had subsequent children. This was seen in the English data particularly where parents who had lost older children could not extend their family. Parents at an older stage of life found it particularly difficult to cope with the loss of their child. The depth and length of the affectionate bond with older children had considerably more history as compared to the bonds with younger children, which presumably contributed in a major way to the difficulties of coping with the loss

Questions 13-16 were found not to be appropriate in the African context. Since death was so common within the communities that the research took place in, it proved difficult to get the interviewee to talk about such losses. In these communities the concept of relatives was much broader in understanding compared to in England. In

England we have clear identified terms for relatives whereas in Uganda and particularly with the Masai in Tanzania, relatives were seen in a more broader way as part of the wider tribe. Equally the question that related to people’s problems before loss become so self evident that asking the question become unnecessary. The problems of war, famine, and the general struggle for life was clear to be seen.

TABLE 37

DID YOU EXPECT TO LOSE A CHILD

EXPECTATION OF LOSS OF A CHILD	YES	NO
Total %	9	91
Uganda % (n=100)	8	92
Tanzania % (n=15)	13	87
	chi-squared = 0.467, df=1, p = 0.494	

The difference between the two samples looking at the expectation of the loss of a child was not statistically significant. One might have expected that in a culture where the mortality rate was high and in an environment where dangers were ever present, that parents would express a realisation that they might well have a child that would die at an early age. However it was surprising to see that 87% of parents in Tanzania and 92% in Uganda did not expect to lose a child (table 37). Is this a form of denial, a mechanism by which people learn to cope with such vulnerabilities of life? From the perspective of a psycho-social transition, it would appear to be far more beneficial to assume your child will survive than to accept the realisation that sooner or later you may well lose a child. The benefits to a parent are far greater if they assume that their

child will survive as compared to the cost of thinking through the outcome of a potential loss. This is very similar to how people cope with parenting in England. As a chaplain of a maternity hospital, it was my task to inform parents only weeks before they were due to give birth, that not everyone leaves a maternity hospital with a living baby. The reaction of the potential parents was one which left you feeling that they did not want to hear what was being said. One can understand why people react in this denying way. To be able to prepare for a birth with all its new experiences requires a general positive framework of thinking. How much more where life is so difficult in an African context.

Question 18 is related to whether the parent might have sensed that something was wrong or that the child would die. However the concept of sensing that something might happen proved to be difficult to communicate clearly in the African interviews.

TABLE 38
MEDICAL HELP

MEDICAL HELP	YES	NO
Total %	84	16
Uganda % (n=100)	84	16
Tanzania % (n=15)	87	13
	chi-squared = 0.07, df = 1, p = 0.791	

Because the Ugandan and Tanzanian sites were based near hospitals, perhaps it should not be surprising that such a high percentage of people received medical help

when relating to the loss of a child (table 38). One suspects that if a survey was carried out only a few miles further away from the hospitals, then this number would greatly drop. The difference between the two samples is not statistically significant.

Although it was difficult to gain clear answers to questions 20 -24, which related to what happened at the point of death, a consistent picture was gained. The expression of feeling at the point of the death of a child was hard for parents to describe. They did however give a clear picture of a mother crying for hours once the child had died. Mothers expressed that this was not, in their eyes, enforced by culture or previous role models. Mothers talked about how they just could not stop themselves from weeping. They seemed to feel that this was beyond their control and when asked whether they wanted to stop crying many said that they did. Parents said that they felt physically exhausted after crying for hours and did not feel that the ongoing weeping and crying helped them.

It has been suggested that crying, weeping, sobbing and wailing is an expression of the mourning process in public. This leads the wider community to enter into the outward expression of mourning. Laugani (1997, p.218) acknowledges that bereaved families are encouraged by the community to display grief openly. Such expressions can be seen as cathartic and hence therapeutic. However the parents interviewed did not necessarily confirm this. Without further analysis one cannot say whether in fact crying and wailing within the first twenty four hours benefits the bereaved or not.

In Tanzania and Uganda it is the tradition to dispose of the body within a very short period of time. This is mainly because of the tropical heat which makes the body decompose fast. Both in Kagando and in Moshi the tradition was to bury the dead within the family’s land. This was usually just within the back garden of a house. The process takes place very quickly as compared to in England when the funeral is often 5-10 days after death.

TABLE 39
COMPANY AT DEATH

COMPANY AT DEATH	YES	NO
Total %	87	13
Uganda % (n=100)	87	13
Tanzania % (n=15)	87	13
	chi-squared = 0.001	

Since a high number of deaths had taken place linked with hospitals it was not surprising that most parents had someone else with them when their child died (table 39).

Talking to nurses and other family members, it did seem that the carers were unsure how to behave or care at times of death. There seemed little attempt to prevent the long weeping process but neither was there any indication that people actively encouraged it.

TABLE 40

HOLDING THE CHILD

HOLDING THE CHILD	YES	NO
Total %	80	20
Uganda % (n=100)	83	17
Tanzania % (n=15)	60	40
	chi-squared = 4.31, df = 1, p = 0.038	

The difference between the two samples relating to holding the deceased child was statistically significant. In the light of the fact that the losses in the Tanzanian interviews involved a higher proportion of older children, one might not have been surprised that there was a lower percentage of these parents holding their child at death (table 40). In the English context no figures were obtained in regards to holding the deceased child. However as a hospital chaplain, I did find that fathers particularly found it difficult to hold a deceased child especially when the loss was a baby. In fact all the males interviewed in Uganda and Tanzania said that they held their child except one man who was injured at the time of loss.

Question 27 on the length of time that parents stayed with the deceased became redundant when one realised that the burial took place within hours of the death. This allowed no further visiting of the deceased, as can take place in England at the mortuary or funeral director's chapels.

TABLE 41

REACTION AT DEATH - CRYING/WEEPING

REACTION AT DEATH	YES	NO
Total %	88	10
Uganda % (n=100)	88	9
Tanzania % (n=15)	87	13
	chi-squared = 1.95, df = 1, p = 0.208	

Question 28 was designed to find out whether bereaved parents felt an initial sense of shock, numbness or a calm feeling. However the overwhelming reaction of parents was simply to express their outburst of crying, weeping and sobbing (table 41). The difference between the two samples was not statistically significant. It proved difficult to perceive why the smaller percentage of parents expressed little or no emotion at the point of death.

TABLE 42

DESIRE TO BE WITH COMPANY

DESIRE TO BE WITH COMPANY	WITH COMPANY	WITHOUT COMPANY
Total %	92	8
Uganda % (n=100)	91	9
Tanzania % (n=15)	100	0
	chi-squared = 1.47, df = 1, p = 0.226	

The large majority of bereaved parents reported that they desired to be with company at the time of death (table 42). The difference between the two samples was not statistically significant. Since the funeral takes place so quickly after the death of the

child, there is little time for the bereaved parents to be on their own. In any case there are far fewer barriers between people in an African context compared to people in England. In the English context there are the barriers of professionalism, relatives living at a distance as well as the simple barrier of the front doors of solid houses.

Question’s 30-35 related to the events that took place around the funeral and the type of help that the bereaved received from the community. It appears that the community do gather around the bereaved within the first few hours of loss and in helping to prepare for the funeral.

TABLE 43
DESIRE FOR PEOPLE TO SEE THE DECEASED BEFORE THE BURIAL

DESIRE FOR PEOPLE TO SEE THE DECEASED	YES	NO
Total %	84	16
Uganda % (n=100)	87	13
Tanzania % (n=15)	67	33
	chi-squared = 4.09, df = 1, p = 0.043	

A high proportion of parents in the Ugandan setting wanted the community to see the deceased child before burial (table 43). The difference between the two samples was statistically significant. In the Tanzanian town situation, this was reduced to only 67%. One reason for the variation may be due to the cultural differences between the town and the country settings. In the Ugandan village, the people were very isolated

and this may have formed more of a close knit community. Although this question was never asked in England, the general impression from interviews was that the majority of parents did not want people to be able to see the deceased. Nevertheless in England the greatest support people gave was in attending the funeral. Funerals for children in England usually draw a large section of the community. Parents expressed that this was in fact the largest comfort to them at a funeral. In the Ugandan context it seems that a willingness to acknowledge the death by observing the child proved to be the point where parents could identify the community's support and understanding. Nevertheless, following the normal customs of a community did not necessarily lead to a feeling of support for the bereaved. Parents expressed how they still felt isolated from the community.

TABLE 44

PEOPLE’S REACTION TO THE LOSS

PEOPLE’S REACTION TO THE LOSS	POSITIVE	NEGATIVE
Total %	47	53
Uganda % (n=100)	42	58
Tanzania % (n=15)	80	20
	chi-squared = 7.57, df = 1, p = 0.006	

Although the Tanzanian community of Moshi seemed to be supportive to the bereaved parents, a different reaction seemed to be taking place within the Ugandan community of Kagando (table 44). The difference between the two samples was

statistically significant. One substantial difference between the interviews in Uganda and Tanzania occurred in the support and reaction of the community. In the more educated urban town of Moshi, Tanzania, 80% of the parents felt that people reacted positively and caringly towards them. Here there was a general acceptance that when death took place it was usually caused by illness. Those interviewed were also part of a Christian community in which the friends and family offered Christian support with their belief. There was a willingness to accept the consequence of death as an act of God. However in Kagando, Uganda, which was in a rural setting, the people practised more of a traditional religion. Here the community appeared to be less supportive, 58% of the parents said that people reacted negatively towards them, often with a sense of blaming the parents. This may account for why there was a higher percentage of parents who felt suicidal in Uganda as compared to Tanzania (59% compared to 33%). It was particularly noticeable that parents felt that the support in Kagando was very short lived. In England, parents found that people often said similar words of comfort or hurt to them. This was also true in the African setting. Table 45 provides some examples of comments offered.

TABLE 45

COMMENTS MADE TO BEREAVED PARENTS IN ENGLAND AND AFRICA

IN ENGLAND	IN KAGANDO & MOSHI
“Why are you crying?”	“What did you do wrong?”
“It was worse for Mrs. Smith.”	“It was your fault.”
“I understand.”	“You were a bad mother.”
“Good will come out of it.”	“You must be cursed.”
“It was the hospital’s fault.”	“It’s one less to feed.”
“He/She’s gone to a better place.”	“You must go to the Witch doctor.”
“My divorce was worse.”	“You must move house.”
“Look on the bright side.”	“You should go back to your other relatives.”
“I know because I lost my dog.”	“It was because you went to the hospital.”
“At least he was sixteen.”	
“He was just trouble to you.”	
“Time heals.”	

The comments illustrate two issues. The first is that people find such deaths extremely hard to handle. They are not used to being in such a position with a bereaved parent who is clearly distressed. This inevitably leads to people trying to comfort and wanting to say something that they think will help. The difficulty of coming up with appropriate words unavoidably leads to unfortunate comments. Second, there is also the fear that is produced within the community. The death of children can lead people

to feel that life with all its complexities is meaningless. It portrays injustice in relation to the fact that children should die after parents and not before. In England, parents expressed a feeling that people avoided them and would even cross the road to prevent conversation. The bereaved parents felt, in connection with schools, that other parents were frightened that the loss of a child might in some sense be contagious. However irrational this might have seemed, it left the bereaved feeling isolated. This seemed equally true in the Kagando situation. The community may have been supportive in the first few days, but people’s reactions seemed to change as time went on. One wonders whether this is tied to a coping mechanism within people which helps them adjust to social situations that they find extremely hard to handle.

TABLE 46
SUICIDAL FEELINGS

SUICIDAL FEELINGS	YES	NO
Total %	56	44
Uganda % (n=100)	59	41
Tanzania % (n=15)	33	67
	chi-squared = 0.32, df = 1, p = 0.572	

Bereaved parents in the Ugandan communities were much more likely to report suicidal feelings than those in the Tanzanian communities (table 46). However the difference between the two samples was not statistically significant. It has to be recognised that the Ugandan community was grappling with other fundamental

problems of existence such as assaults and killings which the Moshi town people did not have to cope with to the same degree.

TABLE 47
BLAME FOR DEATH

BLAME FOR DEATH	GOD	EVIL	NONE
Total %	58	22	20
Uganda % (n=100)	61	25	23
Tanzania % (n=15)	40	0	60
	chi-squared = 10.82, df = 1, exact p = 0.005		

Of parents in Kagando, 61% blamed God for the death of their child as compared to 40% of parents in Moshi (table 47). However when it came to attributing blame to an evil presence, then 25% of parents in Kagando answered affirmatively as compared to no parents in Moshi. The difference between the two samples was statistically significant although the cell counts were small. This difference was due to the religious belief systems encountered in the two settings. It was interesting to note that, as parents answered this question, one felt that the term God and evil could have been interchanged. Somehow in the parent's mind both were equally involved. It seemed that the religious background simply influenced the kind of terminology that came most readily to peoples minds. The high percentage in Moshi who said that they blamed no one for the death (60%) probably relates to them attributing the death to illness (60% of the deaths in Moshi were acknowledged as being due to illness). The

parents were asked separately whether they blamed themselves for the loss (Table 48).

TABLE 48
BLAMING SELF FOR THE LOSS

BLAME FOR DEATH	SELF
Total %	32
Uganda % (n=100)	34
Tanzania % (n=15)	20
chi-squared = 1.17, df = 1, p = 0.25	

The differences between the countries are difficult to clarify. In England, parents interviewed were more expressive in communicating how guilty they felt about the loss. This variation could possibly be due to parents feeling less powerful in a poorer society as compared to the western parents who have a fuller education and greater resources at hand to utilise.

Bereaved parents were unable to relate to the question 45 on whether their general health was affected by the loss of a child. In the west there is a culture of being aware of ones own well being and being knowledgeable about ones own health. In the African setting there was just not that kind of understanding or knowledge.

TABLE 49

THINKING ABOUT YOUR CHILD

	WHAT MAKES YOU THINK ABOUT YOUR CHILD			
	FOOD	CHILDREN	DEATH	OTHER
Total %	11	33	10	46
Uganda %(n=100)	13	32	10	45
Tanzania % (n=15)	0	40	7	53
	chi-squared = 2.55, df = 3, p = 0.466			

The African parents expressed how meal times, night time, and seeing other children influenced their thinking about their loss (table 49). The presence of other children was clearly a factor, as in England. The difference between the two samples was not statistically significant.

TABLE 50

HARDEST TIMES SINCE LOSS -ENGLISH DATA (MERRINGTON 1996)

		SEX		TIME SINCE DEATH			
HARDEST TIME SINCE LOSS	Total No.	MALE %	FEMALE %	0-2 yr	3-5yrs	6-10yrs	10yrs+
CHRISTMAS	56	66	44	75	71	39	50
HOLIDAYS	25	31	16	25	33	17	20
ANNIVERS.	60	72	44	75	67	56	50
BIRTHDAYS	51	56	44	-	71	39	50
MOTHERS DAY	5	3	8	-	8	-	10
FATHERS DAY	2	-	4	-	4	-	-
END OF TERM	2	3	-	-	4	-	-
OTHER (NO DETAIL)	18	16	20	-	21	22	10
NO ANSWER	14	9	20	25	-	17	30

One can from table 50 see that in England, there remain key times in the life of the bereaved that still affect them. Half of the parents after ten years or more still found Christmas, anniversaries and birthdays difficult to handle. However in Africa parents did not have specific dates to recall. Birthdays are not remembered and not therefore celebrated. Questions such as No. 47 (How did birthdays and anniversaries affect you) simply made no sense to the bereaved parent. The date of diagnosed illness or death would equally not be noted. Yet there would be specific times of recall apart from daily thoughts of the deceased. In both countries the general presence of other children would act as a prompt for recall, with 99% of bereaved parents expressing

pain at seeing children of the same age as the deceased (table 51). The difference between the two samples was not statistically significant.

TABLE 51
REACTION WHEN SEEING CHILDREN THE
SAME AGE AS THE DECEASED

REACTION WHEN SEEING CHILDREN SAME AGE AS THE DECEASED	YES	NO
Total %	99	1
Uganda % (n=100)	100	0
Tanzania % (n=15)	93	7
	chi-squared = 6.73, df = 1, exact p = 0.130	

The fact that death was such a regular occurrence for the African sample would also provoke recall. This is precisely opposite to the idea that commonplace death might reduce the prevalence of severe long term grief. Yet this is also different from the English data, where parents feel very isolated in their loss which is why they find support in groups such as the Compassionate Friends.

Almost all of the bereaved parents (98%) said that they felt it helped them that the rest of the community had also experienced loss (table 52). This was not because people supported the parents any better but simply because the bereaved did not feel they were alone in their experience. The difference between the two samples was not statistically significant.

TABLE 52

DOES THE HIGH NUMBER OF DEATHS

IN SOCIETY HELP

DOES THE HIGH NUMBER OF DEATHS IN SOCIETY HELP	YES	NO
Total %	98	2
Uganda % (n=100)	89	11
Tanzania % (n=15)	100	0
	chi-squared = 1.83, df=1, p=0.177	

What was unknown was whether the people could imagine a case where death was not a daily occurrence. In Kagando where the life style for a mother was very basic, she would find feeding time a particularly difficult period. A range of other answers were given that drew the parents attention to their loss (Table 53). Parents were not asked to give more than one answer therefore it is not known how many of these factors were affecting the parents collectively.

TABLE 53

WHAT MADE PARENTS THINK ABOUT THEIR LOSS

Children the same age (Uganda 32%, n=100; Tanzania 40%, n=15)
When others die (Uganda 10%,n=100; Tanzania 7%,n=15)
Feeding time (Uganda 13%,n=100; Tanzania 0%,n=15)
When in need (Uganda 6%,n=100; Tanzania 7%,n=15)
At work in the hospital (Uganda 5%,n=100; Tanzania 0%,n=15)
When I see other babies (Uganda 4%,n=100; Tanzania 0%,n=15)
Night time (Uganda 4%,n=100; Tanzania 0%,n=15)
Do not think about the child (Uganda 3%,n=100; Tanzania 14%,n=15)
Breast feeding (Uganda 3%,n=100; Tanzania 0%,n=15)
Buying flowers when I have money (mentioned only once or twice)
Seeing the grave daily (mentioned only once or twice)
When I see boys (mentioned only once or twice)
Seeing goats (mentioned only once or twice)
Mornings (mentioned only once or twice)
When sickness is in the family (mentioned only once or twice)
Pregnant mothers (mentioned only once or twice)
When I dream (mentioned only once or twice)
Seeing the school (mentioned only once or twice)
Seeing an empty plate (mentioned only once or twice)
Called by the child's name (mentioned only once or twice)
When holding a child (mentioned only once or twice)
Children playing, the sound of children (mentioned only once or twice)

When parents had daily recall of their loss, many parents expressed that they felt emotionally angry about their loss, especially in Uganda (table 54). The difference between the two samples was statistically significant. This may well be because of the ongoing problems with rebel activity within the Kagando community in Uganda as compared to the more stable lifestyle of the Tanzanians in Moshi.

TABLE 54

DID YOU FEEL ANGER

DID YOU FEEL ANGER	YES	NO
Total %	89	11
Uganda %	95	5
Tanzania %	47	53
	chi-squared = 30.39, df = 1, p=< 0.001	

There was a particularly high number of parents who expressed the experience of sensing the deceased along with talking to the deceased (table 55).

TABLE 55

SENSING AND TALKING TO THE DECEASED

SENSING THE DECEASED	YES	NO	TALKING TO THE DECEASED	YES	NO
Total %	87	13	Total %	90	10
Uganda % (n=100)	90	10	Uganda %	94	6
Tanzania % (n=15)	67	33	Tanzania %	60	40
chi-squared = 9.80, df=1, exact p=0.007			chi-squared = 16.13, df = 1, exact p = 0.001		

The statistically significant differences between the two African cultures lie in the different belief systems. In the Ugandan context there was a strong belief in the ‘living dead’ concept. This was far less pronounced in the more christian culture of

the Tanzanian town. The idea of sensing the deceased's presence is not a new one, nevertheless in Africa this has added meaning as compared to in England. Only 19% of people interviewed in England acknowledged any experience of a close presence of the deceased. More will be said of this when questions of religion are looked at. Although direct questions about talking to the deceased were not asked in the English research, some individual parents when interviewed talked about how they would engage in a form of dialogue with the deceased child.

Questions 55 - 68 that related to time concepts did not work effectively within the interview. Parents could relate to the concept of 'at the time of death' or 'in the present,' but to differentiate about the period in between the death and the present time was hard for the parent to grapple with, particularly with the added difficulty of translating to and from English.

There was a relatively small percentage of parents who held on to possessions associated with the child. In Kagando parents simply did not have any special belongings to hold on to, whereas in Moshi there was a slightly higher degree of material affluence in which the children might have had personal belongings (table 56). This explains the statistically significant difference between the two samples.

TABLE 56

HOLDING ON TO POSSESSIONS

HOLDING ON TO POSSESSIONS	YES	NO
Total %	37	63
Uganda % (n=100)	10	67
Tanzania % (n=15)	67	33
	chi-squared = 6.32, df = 1, p = 0.012	

There was general difference from the west where parents have so many clothes, toys etc. belonging to the child, as well as a large number of photographs. In Africa however, it was rare for a parent to have a photograph of their deceased child. Yet for all the difference in material and personal belongings, parents in Africa expressed their daily recall of their child in a similar way to the British parents. What was not clear from the African data was whether parents recalled their deceased child irrespective of what might have prompted their recall. This is just as true for the English data. Further tests would need to be carried out with parents in both cultures to see whether parents had recall when the factors that commonly seem to prompt recall are removed. It is still therefore unclear whether long-term grieving for a deceased child is mediated by cognitive representations, not merely by material artefacts. The difficulty for parents is that they are surrounded daily by many physical reminders of their loss. Part of the daily recall of the deceased in Africa was the fact that the child would have been buried very close to the home of the parent. Adults spend a reasonable amount of time on their land growing crops, which would be close to the grave. A major part of their day is therefore spent outdoors so the grave would be constantly on view,

Eighty-eight percent of parents said they visited and cared for the grave with the majority of the remainder unable to visit the grave due to relocation (table 57). The difference between the two samples was statistically not significant.

TABLE 57

VISITING THE GRAVE

VISITING THE GRAVE	YES	NO
Total %	88	12
Uganda % (n=100)	89	11
Tanzania % (n=15)	80	20
	chi-squared = 0.99, df = 1, p =0.320	

The difference between the two samples in response to Question 86 that related to where the parent believed the deceased child was now, was statistically not significant (table 58).

TABLE 58

WHERE IS YOUR CHILD NOW

WHERE IS YOUR CHILD NOW	HEAVEN	IN THE GROUND	DON'T KNOW
Total %	77	12	10
Uganda % (n=100)	75	14	11
Tanzania % (n=15)	93	0	7
	chi-squared = 2.90, df = 2, p = 0.234		

In Moshi the parents expressed a greater degree of confidence in hoping to see their child again, 93% said they believed that their child was in heaven or with God and 86% said that they hoped to see their child again (table 59). In Kagando there was still a high prevalence of belief in the afterlife and the hope of reunion. The difference between the two samples was not statistically significant.

TABLE 59

WILL YOU SEE YOUR CHILD AGAIN

WILL YOU SEE YOUR CHILD AGAIN	YES	NO	DON'T KNOW
Total %	75	12	13
Uganda % (n=100)	73	13	14
Tanzania % (n=15)	86	7	7
chi-squared = 1.29, df = 2, p = 0.524			

Both communities, irrespective of their religious belief, held on to the traditional African view of the concept of the 'living dead'. This was why it was important for the child to be buried close to the house along with other deceased relatives. The question ‘do you believe in the living dead,’ was added after initial discussions with community leaders when it was clear that this was an important issue in the cultural setting. The findings are shown in table 60. The difference between the two samples was not statistically significant.

TABLE 60

DO YOU BELIEVE IN THE LIVING DEAD

DO YOU BELIEVE IN THE LIVING DEAD	YES	NO	DON'T KNOW
Total %	59	12	3
Uganda % (n=100)	59	38	3
Tanzania % (n=15)	60	40	0
	chi-squared = 0.47, df = 2, p = 0.792		

The 'living dead' concept is the belief that the spirit of the deceased is still present and can be a protection against evil spirits. This view was particularly important in Kagando where many parents were treated negatively after the funeral. Bereaved parents talked of how people would blame the parent by saying they were cursed or had been a bad parent for such a death to occur. Others would tell the parent that they should have gone to see the local witch doctor rather than to have gone to the hospital. Talking to hospital workers, a broader picture was obtained of how ill patients in the hospital would often also rely upon the witch doctor for their medicine. Some parents went to a witch doctor to seek a breaking of any curse that they felt they might be under. By burying the child near the parent, bereaved parents said that they would hope that they themselves would be protected from curses by the deceased. There was therefore a mixture of local religious beliefs blended into the newer Christian views.

With such an ongoing belief system, it seems that parents have to grapple with their loss over a period of time. One interpretation is that the ‘living dead’ concept means that parents are not able to forget or put the loss out of their mind as easily as they might if the concept did not exist. However an alternative interpretation is that this ‘living dead’ concept is a way of recognising persistent grief over a period of time. If people remain in long term grief, then talking about it in terms of a religious experience of the presence of the deceased, allows the community to rationalise such behaviour. It does at least allow the bereaved to understand their persistent grief and to justify it in a public way.

From the Shadow Grief Interview Schedule the questions were arranged to highlight both the general emotional state of the bereaved as well as to look specifically at whether the concept of Shadow Grief was present.

There were six specific questions that seemed to focus on the long lasting awareness of the bereaved in regards to the deceased.

These questions consisted of :-

No. 53 Did you sense the presence of your child?

No. 54 Did you still talk to your deceased child?

No. 69 Do you still have possessions of the child?

No. 75 Do you visit the grave of your child?

No. 86b Will you see your child again?

No. 94 Do you believe in the 'living dead?'

From the data within these questions, the answers were transferred into a simpler format of ones and zeros denoting affirmative and negative answers. From this data correlation coefficients (phi correlations) were calculated (table 61).

TABLE 61
CORRELATIONS BETWEEN QUESTIONS 53,54,69,75,82,86,94. ON
LONG-LASTING AWARENESS OF THE DECEASED

	Q53	Q54	Q69	Q75	Q94	Q86b
Q53	1.00					
Q54	0.50 P<0.001	1.00				
Q69	0.09 P=0.34	-0.06 P=0.52	1.00			
Q75	0.24 P=0.01	0.08 P=0.39	0.094 P=0.33	1.00		
Q94	0.01 P=0.93	-0.07 P=0.45	0.04 P=0.69	0.06 P=0.56	1.00	
86b	-0.13 P=0.18	-0.14 P=0.14	-0.08 P=0.42	0.06 P=0.54	0.17 P=0.07	1.00

There is a statistically significant correlation here between questions 53 with 54 and 53 with 75 which refer to the deceased and sensing a presence of the deceased child. It is understandable that the parents who still sense the presence of the deceased would also visit the grave and seek to talk to the child. Although it was disappointing that this set of questions do not hang together sufficiently well to provide a measure

of shadow grief, the three interrelated questions do identify an aspect of the shadow grief concept most relevant to the African interviews.

A second analysis was carried out with the African data looking at general emotional grief factors. The questions consisted of:-

No.26 Did you hold on to your child?

No.28 How did you react at the time of death?

This question was originally devised to look at whether the parent experienced either a sense of shock, numbness or a calm feeling. However in the actual interview setting the question, through interpretation, became a question of whether the parent cried for a period of time.

No.29 Desire to be with company at the time of loss? This was also a modified question out of the original question of who helped at the time of loss.

No.34 Did you want people to see the deceased at the funeral?

No.39 Did you have suicidal tendencies?

No.49 Did you experience anger?

TABLE 62
CORRELATION COEFFICIENTS BETWEEN QUESTIONS 16,28,29,34,39.

	Q26	Q28	Q29	Q34	Q39
Q26	1.00				
Q28	0.13 P=0.16	1.00			
Q29	-0.10 P=0.29	0.38 P=0.69	1.00		
Q34	0.36 P<0.001*	-0.06 P=0.52	0.13 P=0.77	1.00	
Q39	0.07 P=0.46	0.22 P=0.02	-0.11 P=0.23	0.03 P=0.74	1.00

The correlations (table 62) were expected to reveal something about the emotional experience of grief in the early stages of loss. A significant correlation was found between the two questions 26 and 34 Why holding on to the deceased child at death was associated with wanting people to see the deceased was unclear. It may be due to the parents wanting acknowledgement and support from the community, thus identifying with them in their loss. Other areas that do not seem to correlate statistically may be a consequence of the complexity of the process of drawing data from an interview that requires translation work in a different culture to the interviewer.

The data was analysed to see if there was a relationship between possible grief indicators, question 53 (sensing the presence of the deceased) and question 75

(visiting the grave) with the child’s age at death and years since the child’s death (table 63 and table 64).

TABLE 63
QUESTION 53 (SENSING THEIR CHILD’S PRESENCE), YES VERSUS NO
RESPONDERS

	THE CHILD’S AGE AT DEATH	YEARS SINCE DEATH
	Median	Median
NO	3.5	9.5
YES	4	4
	Mann-Whitney U=527.5, p=0.557	Mann-Whitney U=351.0, p=0.21

TABLE 64
QUESTION 75 (VISITING THE CHILD’S GRAVE, YES VERSUS NO
RESPONDERS

	THE CHILD’S AGE AT DEATH	YEARS SINCE DEATH
	Median	Median
NO	4.5	4.5
YES	3.5	4
	Mann-Whitney U=983.3, p=0.722	Mann-Whitney U=1038.5, p=0.968

In table 63 it can be seen that the relationship between question 53 (sensing the deceased) and years since death was not significant. It is expected that, over a period of time ranging from four to over nine years, parents would gradually adjust to their

loss and have a decreasing sense and awareness of their thoughts of the deceased child.

TABLE 65
COMPARISON OF QUESTION 7 (YEARS SINCE LOSS) FOR THOSE
ANSWERING YES AND NO TO QUESTION 39 (FEELINGS OF SUICIDE)

	YEARS SINCE DEATH
	Median
YES	4 years
NO	4.75 years
	Mann-Whitney U=1452.0, p=0.309

From table 65 it can be seen that there was no statistically significant relationship between those feeling suicidal and the period of time since loss. There was also no significant difference between the Ugandan and the Tanzanian data (chi-squared =3.48, df=1, exact p = .093).

TABLE 66
COMPARISON OF QUESTION 7 (YEARS SINCE LOSS) FOR THOSE
ANSWERING YES AND NO TO QUESTION 49 (FEELINGS OF ANGER)

	YEARS SINCE DEATH
	Median
YES	6.0 years
NO	4.0 years
	Mann-Whitney U=561.5, p=0.368

From table 66 it can be seen that there was no statistically significant difference between feeling anger and the period of time since loss. However the Ugandan parents were significantly more likely to report feeling anger than the Tanzanians ($\chi^2=30.39$, $df=1$, exact $p < .001$). The Ugandan parents were in a very different context to the Tanzanian parents. It would be necessary to explore whether these higher levels of anger in the Ugandan parents were due to the rebel activity and the high level of killing taking place around that geographical area and not due to the child loss.

TABLE 67
COMPARISON OF QUESTION 7 (YEARS SINCE LOSS) FOR THOSE
ANSWERING YES AND NO TO QUESTION 86b (SEE THE CHILD AGAIN)

	YEARS SINCE DEATH
	Median
YES	4.0 years
NO	4.0 years
DON'T KNOW	6.0years
	Kruskal-Wallis statistic = 3.674, $df = 2$, $p = .159$

From table 67 it can be seen that there was no statistical relationship between beliefs that parents would see their child again and the period of time since loss. There was also no significant difference between the Ugandan and the Tanzanian data ($\chi^2=1.30$, $df=2$, exact $p = .539$).

CONCLUDING THE INTERVIEWS

At the end of each interview an attempt was made to finish on a positive note. This partly was left to the interpreter to engage in a more positive discussion with the bereaved parent. Nevertheless the thanks received at the end of the interview suggested that a majority of parents found it beneficial to be able to talk about their loss. Positive comments to the interpreter were passed on which conveyed the feeling that the parents were grateful in having an opportunity to talk of their experience. Two examples of the interviews can be found in the appendix (appendix 11 & 12).

When it came to interviewing the Masai in Tanzania, it proved to be difficult to gain permission from the community leaders. However a small amount of interviewing did take place (appendix 13).

DISCUSSION OF FINDINGS FROM THE AFRICAN INTERVIEWS

Despite the difficulty of interviewing in a different culture using an interpreter, various points of reflection can be drawn from the data obtained.

QUESTIONNAIRE MODIFICATION

One of the main aims of the research was to identify what it was like for parents to lose a child over a period of time in a different context to the English data. However despite having back-translated the questionnaire and adjusting it accordingly, it was

found that there was great difficulty in communicating some of the meanings of the questions to the parent via the translator. The questionnaire become reduced and was used as much as a tool to guide the conversation with the parents, than as an analytical and quantitative measuring device. This has led to a failure in the analysis to reveal a full picture of what it was like for the grieving parents in their cultural context and to fully appreciate the transition that the parents had made in their grief over a period of time.

The approach of finding parents willing to be interviewed led to a female-friendly sampling that was not initially expected. The fact that the interviewing took place via a hospital led to this high level of female respondents. Anyone in hospital needed a relative or friend to be available to look after them in terms of cooking and washing clothes etc. This was a clear female role within the community. It was therefore understandable that those who responded to the request to be interviewed would more likely be female while most of the men were out in the fields working or involved in defending the geographical area from rebel activity. A number of writers argue that men and women still inhabit different cultures, and that these different experiences go a long way to explaining the apparently unequal division of emotional work within families (Altschuler, 1993; Duncombe and Marsden, 1995).

It is unclear whether questioning people who are already in a vulnerable environment surrounded by illness are more likely to find themselves having an increased

awareness of their losses. It cannot be ruled out, therefore, that the findings are particularly affected by the unusual context that the interviewing took place in and that what was actually being measured was a form of grief with memory. There was also the added affect that although no reward was ever mentioned, the fact that a white person was carrying out research may have led to some individuals to thinking that they may receive some kind of assistance. This raises the possibility that the parents may have given answers that they thought the interviewer wanted rather than what they actually thought. However the interpreter was surprised at some of the answers he received. It seems unlikely that the parents could have adjusted their answers, nevertheless in such an environment the possibility needs to be acknowledged.

The high level of multiple losses was an additional factor in the interviewing that made it difficult for the interview to separate out the impact of the various losses. Although the interview was supposed to focus only upon one loss, it was difficult to assess how the other losses impinged upon the interview. The high level of dependence upon the interpreter to explain and to clarify to both the interviewer and the interviewee added to this situation. On the other hand, one of the purposes of carrying out this research in these communities was to investigate grieving in communities with a high prevalence of loss.

It was unfortunate that although one hundred parents were interviewed in Uganda, only fifteen were found in Tanzania and there was an almost total reluctance to be interviewed by the Masai community. This makes any comparisons between the sites difficult with such small cell samples in some categories.

In light of these factors, any future research in this field would benefit from focusing the interviewing upon a non-western country where the bereaved spoke English or where the interviewer was fluent in the native language. Focusing upon one area of analysis for a longer period would also assist in gaining insight into the background of the community. Interviewing people in a more natural context away from hospitals would also help and may result in a more balanced response from males and females.

Very little emotion was shown during the interview by the parents. It was difficult to interpret this. It could have been due to the unusual experience of being interviewed by a white Englishman, the difficulty of the interpretation, or the fact that it was not a culturally accepted behaviour to do so, or the fact that the loss of a child was less traumatic in the African culture. The culture clearly allowed for the bereaved to cry at the point of death but it was unclear whether it was frowned upon to express emotion months or years later. However one interview which involved an educated man from Moshi in Tanzania did express emotion in a very similar way to a western person (appendix 8). This raises questions about the difference between the emotional- psychological expression of grief as compared to the mourning process

which is far more culturally controlled. One might assume that human nature is such that people experience similar emotions throughout the world which are then tailored according to the cultural traditions of the persons background. In a more individualistic country one could expect people to express their grief in a way that shows little regard to the tradition of previous mourning forms. In a culture such as the two African settings one would not expect individuals to show their own style of mourning due to the corporate nature of their existence. One might see the expressing of grief over time as a luxury which can only be afforded in a context where the struggle for life has been simplified and secured. In the African context, there are so many struggles on a daily basis, that although one feels the emotional trauma of loss, nevertheless one has to continue to focus upon the daily routines of survival.

NUMBER OF LIVING CHILDREN

The number of children alive within the family at the time of the interview was exceptionally high compared to English families interviewed. Only five parents actually had no surviving children. There is no doubt that the complexity of life for a family in the locations interviewed, along with caring for several children, was a very demanding lifestyle. When families had experienced multiple losses, the parent was asked to talk about the most recent loss. There may have been greater despair among the multiple bereaved, but this was not revealed due to the lack of sensitive measurements within the bereavement inventory or the fact that it was simply not present. It was difficult to differentiate between evidence of parents maintaining

distinct bonds with each of the deceased as compared to forming a merged memory of their loss. One view is that those who have encountered multiple losses reach a 'ceiling effect' of emotions such as despair which simply cannot reach a higher level. Or there may be psychological defence mechanisms in operation, at least in the individuals who survive well enough to be available and willing to be interviewed. Further research would be needed to sort out these possibilities.

However it appeared clear from the interviews that parents had very clear memories of their deceased children regardless of the number of children in the family. One parent who had seventeen living children and had lost one child nineteen years previous, had still held on to the deceased child's bracelet. Another women who had lost two children out of twelve children in her family said,

“I like to talk about my dead children. When I do it haunts me. If I think about it, it affects me, but on the whole it does affect me at all” (Interview of a Ugandan mother).

CHILD'S AGE AT DEATH

The age of the child at death was spread over a broad age range and not just very young children. It is obvious that parents who are older at the time of loss have less chance of becoming pregnant and rearing more children.

In many respects the African mothers would spend a greater amount of time with her children in rearing them as compared to the English mother. The African mother

would have the child with them throughout the day even if they were working.

Parents did express how the bond that was formed and developed with a child over the years was more significant to them than a loss of a baby.

“Better to lose a baby than an older child because of the sweetness of the relationship.”(Interview of a Ugandan mother).

It is more painful to lose an older child because he has helped you more in the past.” (Interview of a Ugandan mother).

Another parent expressed how he felt it was better to lose a child than a wife.

“It’s better to lose a child than a wife because the daughter cannot be a wife but a wife can give another baby.” (Interview of a fifty year old Ugandan father who had lost a child nineteen years ago).

Both of these last two interviews reveal a very practical view of how some parents view their family. This portrays their struggle for existence in a difficult environment and the need of a family to assist in their survival. In this context, the older child represents more of a support to the family than a young baby.

In the African situation there did not seem to be any complication of the older deceased child leaving any legal complexity. Nevertheless parents were able to express how the loss of an older child was particularly difficult.

“ I miss my son coming and visiting me late at night. He would always bring a little sugar and other food if he could afford it. He would sit with me by the fire and as we talked I often felt that my problems were less. I knew that if I had to go to hospital he would have helped me pay the bill.”

(Interview of a Ugandan mother. The mother lived in a simple mud hut with nothing in the home except a mattress, one blanket and one saucepan on a simple fire.)

TYPE OF DEATH

Ninety percent of those interviewed had lost children through illness. The remaining ten percent had lost a child through accident (4%), murder (5%), and suicide (1%). To understand the long term impact of the loss of a child through deaths other than illness, one would require a larger data base. It is not known whether the stigma of losing a child through murder or suicide prevents parents from coming forward for interview. Certainly those interviewed whose child had been murdered were very open in talking about their loss. Due to the inability of measuring emotional grief factors in an African situation accurately it was not possible to detect whether factors such as anger were more present than in other losses. However as in Beirut (appendix 6),

parents of murdered children did have to cope with the possibility of the murderer being within their vicinity. This clearly was a complicating factor which kept the issue of the loss very much to the forefront of the bereaved parents' minds. In Beirut, the intensity of the loss was maintained due to the ongoing danger of further civil war and flare up of potential local killings. In the African study sites danger was equally present, but this atmosphere was difficult to quantify due to the language and culture barrier.

THE PROCESS OF DEATH

Over 75% of deaths involved a degree of anticipatory grief. In the light of research into anticipatory grief one might have expected that this would have reduced the emotional intensity of grief present in the parents. However there seemed to be no radical difference between parents whose child died suddenly as compared to those who were ill for seven days or more. A difference within the African setting as compared to the English one is the amount of information that is shared with parents when a child is ill.

In England if the prognosis is poor, usually parents are given time to prepare for the potential loss. There is also a considerable amount of information gathered by the parents about the illness, whether it be from hospital staff or from information within the general public domain. Yet in the African situation, parents have very little access to any information about the illness of their child. Whether a parent takes their child to

the hospital or to a witch doctor seems to depend upon their degree of trust in people rather than basing decisions upon information and hard facts.

THE EXPECTATION OF LOSING A CHILD

In a culture where life expectancy is low and the general death rate is high it was surprising that parents did not admit to expecting to lose a child. In the environment of the interviews there was medical help available, although at a price, and 84% of children who died received medical support. However the hospital may have been two or three hours walk from the family home. One might think that parents have large families because they expect to lose a child in their upbringing. However this does not seem to be the case with 92 % of parents in Uganda and 87% of parents in Tanzania saying that they did not expect to lose a child. There is little if any, family planning teaching, and no availability of birth control. One reason for the large number of children in families is that the greater number of children can provide more assistance upon the farm land. However talking to the local medical doctors, there seemed to be a growing trend among the educated to plan for smaller families especially if they wanted to pay for an education for their children.

Why did only 9% of parents ever expect to lose a child in a typical family of eight children? One would expect families in the West with smaller family units and excellent health care not to expect to lose a child. Perhaps this percentage reveals the degree in which parents, mothers in particular, hope and desire for the very best for

their babies. It also reflects the attitude of those interviewed in England who felt that although children die, it could not happen in their family. A kind of 'self survival' attitude perhaps prevails in all cultures. This could account for why communities struggle to cope with bereaved families over a long period.

There has been research carried out on the subject of unrealistic optimism. The term was given by Weinstein (1980) to the phenomenon where judgements about risk to oneself are more optimistic than judgements about risk to a typical 'average' other. Cross cultural comparisons have been made. For example, one recent study found unrealistic optimism about future life events present in European, American and Japanese subjects, with Europeans and Americans showing higher levels of optimism bias than the Japanese (Chang, Asakawa & Sama, 2001). The concept of unrealistic optimism could easily be applied to the observation that parents do not expect to lose a child, even in African contexts where childhood death occurs at a higher rate than in England. This does not really explain what is going on, but it suggests that we are looking at a phenomenon that is much broader and more general than just responses to the loss of a child.

The 'conspiracy theory' that seemed to exist in England appears to be present also in other cultures. There was an attitude in England almost as if child loss was contagious such that people seemed to avoid the bereaved parents. The underlying thought may well have been that parents did not want to think about the vulnerability of their own

children and therefore avoided contact with the bereaved parents, who then experienced this behaviour by others as though child death was contagious. The consistency of avoidance made the bereaved parents feel as if people had collectively decided to avoid them, hence bereaved parents felt ostracised by the community. In Africa, this sense of self denial of the reality of the vulnerability of life for one's children could be part of the same self protection mechanism.

REACTION AT DEATH

Within the western society there has been a growing tendency for death to take place within a clinical Hospital or Hospice. This seems to provide an element of control over how the bereaved react at the point of death. Excessive initial grief in the form of tears and outward expression is relatively restrained. However in the African context even within the Hospital environment there was a far greater overt reaction by grieving parents. Parents are usually supported by another member of the family or relative.

Eighty percent of parents held their child at the time of death and many would go on holding for a prolonged period of time. This holding is increased by the fact that the parent would need to carry the dead child home within hours of the death ready for burial on the parent's land. This would generally take place within 24 hours of the death. As compared to the west, where a parent may briefly cuddle or hold the hand of their deceased child, in Africa the parent would be holding the child often for hours

after death. In Uganda, 85% of parents said that they held their child. The length of time of holding seemed to vary according to whether the loss took place in a hospital environment or at the parent's home.

Data was not obtained specifically to clarify the difference between how parents grieve at home as compared to in the hospital. Mothers expressed their grief by crying, which could continue for several hours, from almost the moment of death. This seemed irrespective of the locality. It was not uncommon on the daily basis in the Kagando Hospital to hear a mother wailing loudly at some point in the day.

When mothers were asked whether they could control the wailing, the bereaved ladies would reply that it was simply a wave of emotion that was uncontrollable. Several expressed how exhausting it was to cry in such a way, and that they would have stopped if they had been able. Others found the wailing and grief so intense that they fainted. Most expressed the feeling that wailing was in fact unhelpful to how they felt within their grief. However with the funeral occurring only hours after death, the wailing may well have provided an intense degree of preparation for the funeral, which in the west would have taken place many days later. There was also more of an open expression of grief at the funeral. All of the funerals would normally take place on the land of the bereaved parent, close to their home. The family and community would be expected to look at the deceased child before burial, 84% of the parents

expressed a preference for people to see the child. They generally felt that it was a sign of love and respect in being able to see the deceased.

GRIEF OVER TIME

In the interviews, parents were able to express their experience of grief and loss, however through the translation it was difficult to detect any difference between those who had been bereaved over a small number of years and those bereaved over many years. No statistically significant relationships were found between parents' responses and time since death. The lack of expression within the interviews did not allow an opportunity to observe any change visually between different parents. Since it was impossible to detect change of voice tone in the dialogue, there were no other clues as to how the parents showed any difference over the years. In Uganda, the fact that the bereaved were immersed in a community under attack and fighting for survival, is likely to have had an influence upon how the parents reacted in the interview. At a time of vulnerability, it may not have been realistic to be able to detect differences within the parents who had different grieving experiences. What made this particularly difficult was the fact that bereaved parents had experienced a range of other traumatic events in their lives subsequent to the loss of a child. This was very different from those interviewed in England. Despite all of this, parents were able to talk a little of the key times in their loss.

In Uganda parents did not have specific dates to recall. Birthdays are not remembered and not therefore celebrated. The date of diagnosed illness or death would equally not be noted. Yet there would be specific times of recall (Table 53, p236). In both locations the general presence of children would act as a recall with 99% expressing pain at seeing children of the same age as the deceased.

“I don’t think about my child every day, but only when I see children about the same age as my child.” (Interview with a Ugandan mother who had lost a four year old child twenty years ago).

Recall would also be provoked by death in the community, especially the death of a child, or in Kagando, where the lifestyle for a mother was very basic, she would find feeding time a particular difficult period.

There was a relatively small percentage of parents who held on to possessions. In Kagando parents simply did not have any special belongings to hold on to, whereas in Moshi there was a slightly higher degree of material affluence in which the children might have personal belongings. This is a significant difference from the west where parents have so many clothes, toys etc. belonging to the child as well as a large number of photographs. In Uganda, it was rare for a parent to have a photograph of their deceased child. Yet for all the difference in material and personal belongings, parents in the African sample expressed some daily recall of their child.

Part of the daily recall of the deceased was prompted by the fact that the child would have been buried very close to the home of the parent. Adults spend a reasonable amount of time on their land growing crops, which would be close to the grave. Also a major part of the day is spent outdoors so the grave would be constantly on view, 88% of parents said they visited and cared for the grave with the majority of the remainder unable to visit the grave due to relocation.

Almost all of the bereaved parents (98%) said that they felt it helped them that the rest of the community had also experienced loss. This was not because people supported the parents any better but simply because the bereaved did not feel they were alone in their experience. Yet equally the community had an affect upon the bereaved in how they reacted with their loss.

“I was encouraged not to visit the grave. It might be unlucky and cause me to lose another child.” (Interview of an Ugandan mother).

“I was afraid that people would blame me.” (Interview of an Ugandan mother).

“People help initially, but tomorrow they have their own problems. Death here is not knew to anyone. This does not mean you get more support because

everyone has problems.” (Interview of a Ugandan father who had lost two of his three children).

RELIGIOUS INFLUENCE

Differences were found between the reaction of the Christian community of Moshi as compared to the more primitive society of Kagando. In Moshi the parents expressed a greater degree of confidence in hoping to see their child again, 93% said they believed that their child was in heaven or with God and 86% said that they hoped to see their child again. In Kagando there was still a high prevalence of belief of the afterlife and the hope of reunion with 75% of parents believing in heaven and 73 % expressing a hope of seeing their child again.

Both communities, irrespective of their religious belief, held on to the traditional African view of the concept of the 'living dead' although it was surprising that the percentage that believed in this concept was only 60% in Uganda and 59% in Tanzania. One might have thought that the figure in Tanzania would have been lower because of the influence of Christian belief.

Irrespective of the Christian influence, it was generally seen as being very important for the child to be buried close to the house along with other deceased relatives. Although the location of the deceased was not asked specifically, in the conversations

it seemed that the majority of children were buried close to the home of the parent. When it was mentioned that the burial was elsewhere, the parent seemed particularly unhappy about the arrangement.

The 'living dead' concept believes that the spirit of the deceased is still present and can be a protection against evil spirits. This view was particularly important in Kagando where many parents were treated negatively after the funeral. People would blame the parent by saying that they were cursed or had been a bad parent for such a death to occur. Others would tell the parent that they should have gone to see the local witch doctor rather than to have gone to the hospital. It was not unusual for ill patients in the hospital to go also to the witch doctor for their medicine. Some parents went to a witch doctor to seek a break of the curse that others might have felt they were under. By burying the child near the parent they would hope that they themselves would be protected by the deceased. There was thus found a mixture of local religious beliefs blended into the newer Christian views.

It is unclear whether the 'living dead' concept related to the psychological reaction of grief, or was it simply a religious cultural factor that was unrelated of the grief outcome. Tribal Africans recognise no sharp distinction between the sacred and the secular. Material and spiritual forces are considered to be intertwined. Those ancestors buried close by are recognised as being able to inhabit their own spirit world and able to visit their families. Therefore in this context it is difficult to separate the

idea of the living dead with their experience of grief and mourning. However Rees (1997) found that in his role as a doctor in Wales, the bereaved were able also to express hallucinating experiences of the dead and of experiencing a sense of the presence of the dead. Some patients rationalised these incidents by using language of dreams or seeing a picture of the deceased in their minds. Others saw these experiences as being very real. In an atmosphere of disbelief Rees found that many chose not to talk about these experiences for fear of the community not believing them. Rees concluded that;

‘It seemed possible that one of the most important and universal concepts of mankind, a belief in the continuation of life after death, with its associated religious and ethical implications, could be based upon a very common experience and that the prevalence of this experience was not generally realised’(p.188).

Rees had found from a previous project that widowhood led to a perception that the dead partner was still close to them (Rees, 1971). Glick, Weis and Parkes (1974) found that a widow’s progress towards recovery is often facilitated by conversation with her husband’s presence. In attachment theory, this is seen as a way for the widow to maintain attachment with the deceased. This allows the bereaved to continue with an identity that is preserved so that they can reorganise their lives in a way that is manageable (Bowlby,1980). This is not seen as leading to a negative outcome. On the contrary, it seems to lead to an increased capacity for independent

action. This is consistent with an attachment theory view of the close bond of a young child to a parent. Attachment is seen not as promoting dependency but instead autonomy based on a sense of security.

How can this be accounted for, especially in bereaved parents? The experiences of the bereaved could be likened to peoples' experiences when they lose a limb. It is common for the person to experience some tingling or pain within the limb that has been removed. It is assumed that the severed ends of the nerves are still stimulating the surrounded tissue. Yet this is a physiological process and has no psychological component. A sense of the presence of the dead is more likely linked to an ongoing yearning for the lost object.

In the next chapter a resume of the concept of 'shadow grief' will take place comparing the data obtained from both England and the African sites.

CHAPTER 7

COMPARISON OF ENGLISH AND AFRICAN DATA

This chapter draws comparison between English and African data and identifies differing aspects of grief reactions in the two cultures. Having reanalysed the English data from the Grief Experience Inventory and the Parental Inter-relationship Questionnaire, does the collective data from Africa and England give evidence for the existence of Shadow grief?

At the outset, the English study was aimed at investigating the effects of child loss upon parents. Identifying the concept of 'shadow grief' was not an aim of the research but from the two questionnaires and the interviews, it did seem that 'shadow grief' was a reality for many parents. The African questionnaire was targeted at looking at whether 'shadow grief' existed and was therefore not produced in a way to draw direct comparisons with the English questionnaires. Due to the difficulties of communication and cultural concepts of time scales the questionnaire was modified further such that it prevented any real direct comparison with the English data. Questions relating to 'coming through bereavement and grief' had simply no meaning in the African concept. If further study was to be carried out with these communities a questionnaire would need to be produced that could draw out more accurate comparisons between various communities in different cultures.

Although difficulties were experienced during the research in Lebanon, Uganda and Tanzania, a breadth of knowledge was gained of the experience of parents who had lost children. It was clear that 'shadow grief' was not seen in the same way as in the English study. Parents were clearly affected by their loss but to what extent the effect were long term was difficult to identify. There was simply too many complicating factors involved in the data collection to be able to say clearly how deeply the parents were affected years after the loss. A greater understanding of the culture where the interviews took place in would have assisted with this analysis. What was required was a longer period of study and analysis in one location.

SIMILARITIES BETWEEN THE AFRICAN AND ENGLISH SAMPLE

Despite the difficulties, similarities between the English and the African parent could be identified. The presence of other surviving children was helpful in forcing the parents to get on with their family life. All the communities were helpful initially, but found it more difficult to provide support long term. The presence of other children of the same age as the deceased proved to be a reminder of the parents' loss regardless of the cultural setting. Parents in each setting found ways of rationalising their loss within their belief system. In the African context this was seen with the parents' belief system in the concept of the 'living dead.'

In regards to the English data obtained, there was clearly a high emotional reaction observed within the parents interviewed. The question has to be asked whether the

parents were expressing their daily and weekly experience of loss or whether the two questionnaires and the interview heightened the parents grief with memory such that it resulted in an emotional reaction from the parents. The parents expressed how they would remember their child on a daily basis. However it is unclear at what level of emotion this takes place at. Parents interviewed were all part of the 'Compassionate Friends' self-help groups which encouraged parents to focus upon their loss on a regular basis. This, along with knowing that they were about to fill in questionnaires and be interviewed relating to their loss may well have resulted in parents producing a high emotional reaction.

It is recognised that the emotional responses observed might have also been due to a number of social factors relating to present day living. This included the fact that the birth rate has dropped with families now consisting of only a small number of children. This inevitably means that parents place more energy into the rearing of their children and inevitably therefore have greater interest and expectations in their development. The West has also become more of a child centred society in which children play a greater part in both the economy of the country through the sales of child products as well as in focus of conversation and attention.

Another social factor that was thought to influence how parents reacted to the death of a child was the alienation of society from facing and encountering the death of

people. The increased provision of the health service, hospitals and hospices has produced a large population that rarely has to see a dying or dead person.

There has been a rise in people's expectations of the provision of health for all ages.

This is especially true for children where the affects of immunisation have considerably increased the chances of a baby surviving its first few years.

In England, the process of remembering the loss was more structured than in Africa with clear markers between their daily recall on their journey of grief. These are characterised by the remembrance of birthdays, anniversaries (the date of death, autopsy, inquest etc.) seasonal occasions such as Christmas, Mothering Sunday, end of term time, and going on holiday. In the African context, the parents do not have such dates to focus upon, nevertheless they have similarly special moments of recall. Meal times, being with other children, the occurrence of another death within the community, seeing the grave daily in the back garden, or at night when alone, all seem to be painful reminders of their loss.

Although the death of any family member may give rise to tension within family relationships, this seems particularly true with the death of children. Differences between the way a husband and wife grieve can increase the likelihood of misunderstandings. There are also difficult decisions to be made about how parents should bring up another child in the shadow of a sibling death. Does the parent become over protective as in the interview of Kelly in Moshi, Tanzania

(appendix 8), or does the parent become extra liberal with the sibling so as to prevent argument and upset. Siblings experience a double loss when their brother or sister dies as they not only lose a sibling but also their mother and father in grief. While sibling responses to the death of a child have been studied over a short time scale, more research is required to understand the long term impact upon sibling loss.

Another factor in the English analysis was the fact that the parents had not experienced a range of other traumatic events in their lives as compared to the Ugandan parents. The English parents had more opportunity to focus upon their loss without the distraction of coping with rebel activity making their daily life problematic. The fact of not seeing death occurring daily within a community allowed the English parents to focus more upon their own personal loss as compared to the losses within the community. Although the African parents indicated that the high rates of death did not prepare them for their own loss, they did acknowledge that they were not alone in their loss. Both in the African context and in England, there seems to be strong support initially for the grieving parents. However both the African and English communities seem to struggle with acknowledging the death of children. This in the end, leads to the bereaved parent's feeling of being ostracised by those around them. The inability of a community to talk about the loss, along with the long lasting nature of the parents grief, in the end compounds the grief within the parent. The parent feels unable to talk about their loss because the community's expectation is that people cope with their loss by not mentioning the deceased.

As previously mentioned, the 'living dead' concept gave an expression for the African parent to recognise the daily presence of the deceased. The English setting did not give rise to this kind of religious expression but parents would equally acknowledge talking to the deceased and wanting to sense their presence. People ultimately adjust their belief systems to cope with their loss in a way that proves to be a comfort to them. This may be connected with a tendency for English parents to become more altruistic. It was not uncommon for these parents to become more involved within charitable organisations particularly relating to reasons for the death of the deceased.

ABNORMAL GRIEF REACTION IN THE ENGLISH SAMPLE

It is difficult to separate the emotional factors that play a part in the grief process from the role of the social setting along with its belief systems within the local community to get a clear view of shadow grief. This ongoing phenomenon of grief needs to be seen in its full psychological and social setting. It is also not possible to say whether the long term signs of grief characterised as shadow grief are restricted to the loss of children. There are various factors that play a part in how a person reacts to loss such that shadow grief could be present. However, when grief is observed over a long period, it has often been diagnosed as perhaps chronic grief, delayed grief, or pathological grief. The question with the English analysis is whether the bereaved parents are showing a "normal" grief reaction or are showing signs of pathological grief with major depressive episodes. In DSM-IV (American Psychiatric Association,

1995) suggestions are made about differentiating “normal” grief reaction from a major depressive episode (eg., feelings of sadness and associated symptoms such as insomnia, poor appetite, and weight loss). A psychological disorder is seen as a psychological component that impinges upon a person’s normal function. In regards to bereavement, DSMIV indicates six categories.

1. Guilt reactions other than guilt about actions taken or not taken by the bereaved around the time of death.
2. Thoughts about death other than the bereaved feeling that they would be better off dead or should have died with the deceased.
3. Morbid thoughts about feeling worthless.
4. Marked psychomotor retardation.
5. Prolonged and marked impairment.
6. Hallucinatory experiences other than the bereaved thinking they are hearing the voice or transiently seeing the image of the deceased.

Guilt about actions taken or not taken by the survivor around the time of death is seen as normal. However some English parents continued to express feelings of guilt years later particularly when it related to the loss of older children.

Parents expressed how they had felt suicidal thoughts in regards to wanting to be with the deceased child. This is seen as a normal reaction, however such thoughts seem to

continue for long periods in some parents. This along with the guilt reaction raises concern as to how the parents were coping.

Parents certainly felt a morbid preoccupation about being worthless in the early stages of grief, but to what extent that remained in the parents is unclear. Parents talked about their altruistic behaviour since their bereavement which did show an ability to look positively within their lives. Parents expressed a change in their understanding of life and of their motivations but did not reveal a marked functional impairment or psychomotor retardation. Thinking that one hears the voice or transiently sees the image of the deceased is classed as a “normal” reaction. This was clearly present in the bereaved parents in the English analysis. However as time progressed parents seemed more to be talking or seeking the advice of the deceased rather than actually thinking they were hearing the voice of the deceased. A dialogue between the parents’ thoughts and questions and how they thought the deceased would answer seemed to be a positive experience in the parent’s minds.

A key element with the English parents was their daily rumination upon their deceased child. This was not as clearly defined by the interviews used in the African context and this proved to be a weakness in the African study. In the English context there did seem to be more factors to encourage rumination eg. belongings of the deceased, the deceased’s bedroom, photographs, and various calendar dates relating to the life and death of the child. It has to be recognised that some rumination is not necessarily to the detriment of the parent and does not lead to dysfunctional behaviour of

withdrawal, depression and avoidance. Parents seemed pleased to talk about their child and had many positive memories. The fact that parents carried a deep sadness with them over the years of what might have been did not seem to prevent them from functioning with their lives. It simply revealed the fact that parents were aware daily of what might have been. This could produce both negative and positive feelings. The loss had in some cases led to a change of lifestyle that the parents felt was to their improvement. Nevertheless, the degree to which the parents expressed their guilt, morbid thoughts and the emotion shown at the interview raises questions as to whether 'shadow grief' was being observed or a more major depressive episode.

To clarify this, research could be carried out in England looking at a broader section of bereaved parents. The need to particularly talk to parents not associated with self-help groups would be beneficial. There needs also to be an attempt at measuring the extent of rumination taking place within a parent and how it was affecting their daily life style. Rather than measuring grief factors from a one-off interview or questionnaire, it would be helpful to measure the parents reaction over a period of time. Using an impact of event scale that uses avoidance and intrusive score questions on a regular basis could reveal a more consistent measurement of the impact of the loss.

CHAPTER 8

CONCLUSION

The experience of bereavement is an encounter that we all meet at some point within our lives. One of the most painful areas of loss is when a baby, child or teenager dies. In recent years the thanatological literature has begun to recognise that there are unique factors relating to parental loss of a child. There has also been growing data that suggests that previous bereavement theories have not told the full story. In the past, grief and mourning was seen as fixed within a predominantly psychological set of understandings and interventions. Descriptions of research very quickly become prescriptions of practice. This gives rise the notion of what people might call 'normal grief.' The predominant idea in the twentieth century was one of grief being resolved by detaching from the deceased, letting go and moving on.

More recently researchers have begun to warn of the dangers of over pathologising grief, particularly parents' grief reactions (Rando,1991). There is also a growing recognition that grief is affected by culture and group history as well as individual psychology (Walters,1999). Walters sees the past theories as postulating a grief process from attachment via emotional pain to autonomy. This clinical lore encourages bereaved people not into permanent communion with the dead but into temporary communion with the deceased. Walters suggests we are going through a revolutionary phase before consensus will be reached. As an example of this change

of thinking Worden has adjusted his tasks view of grieving to say that the bereaved need to find an appropriate place for the dead in their emotional lives (Worden, 1991).

Against the backcloth of this development, research was carried out in England to investigate the long term affects of the loss of a child (this research was part of a M.Phil. in theology with Birmingham University). Using two questionnaires and an interview technique, data was collected from bereaved parents who had contact with the self-help organisation called Compassionate Friends. Conclusions drawn from this data showed that parents were showing grief symptoms well after most grief theories would have predicted. Ten and fifteen years later, parents expressed how the loss was still affecting their lives on a daily basis. Marriages were weaker, interest in work and career was muted, and parents generally seemed to grieve in a way that was appropriate for them rather than for their partner. Parents continued to hold on to possessions of the deceased and had often not altered the bedroom of the child. Parents expressed how they had daily recall of their loss such that it still affected them. This was not just exhibited at key emotional times such as anniversaries, birthdays, Christmas and holiday time, but on a more daily basis. There was an alteration in the bereaved's relationship with family, friends, and community. There was also a clear difference of effect for parents who were young enough to rebuild their lives by having other children, as compared to older parents who had lost teenagers and older children who found it considerably more difficult to put together their lives with any sense of purpose or vision.

Although no direct research was carried out towards siblings, it was clear that parents felt that their surviving children were left with problems of their own. Here it seemed that the siblings had experienced a double loss, not only of their brother or sister but also their parents in their grief. Although research has been carried out by others on this subject since 1995, it seems that further understanding of sibling reaction post loss would be beneficial (Hogan and DeSantis, 1994; Corr and Corr, 1996; Schwab, 1997; Miller, 1998; Riches, 2000).

Reanalyses of the English data took place to attempt to clarify the nature of 'shadow grief' (Knapp, 1986). It appears that the factor that relates most closely to shadow grief is the tendency for parents to ruminate upon their loss. It has been argued that the grief exhibited by parents years later is not simply delayed grief, chronic grief or disfranchised grief. There is no doubt that the parent's experience shows some overlap with all of these kinds of grief. It is possible that what had been measured was a form of grief with memory. This needs to be clarified by further research particularly with bereaved parents who are not part of self-help support groups as participants in such groups may not be fully representative of bereaved people in general. However parents themselves, who become extremely knowledgeable of this subject, express how they see themselves as people who are moving on with their lives yet maintaining a bond with the deceased child.

It seems that the concept of 'shadow grief' suggested by Knapp (1986) was present within the parents interviewed, although the depth of emotion present needs to be clarified. It is not clear whether this emotional reaction was simply due to our English culture which has become more child-centred. Families are smaller units today with a greater emphasis upon child rearing and the expectations of seeing your child into your old age are taken for granted.

Further research was carried out to see if shadow grief was present in other cultures where child loss was more common. After further literature search, an initial investigation was carried out in Beirut, Lebanon. This research was curtailed due to ongoing bombing action while interviews were taking place. However, even from the small number spoken to, it was clear that parents were continuing to mourn the loss of their children several years later despite loss being common within the country over many years.

More detailed research was then carried out in Africa focusing upon three regions within the continent. Once again a detailed interview schedule was produced (after a back translating process was completed) and parents were interviewed in Kagando (Uganda), Moshi (Tanzania) and in Masai community on the foothills of Kilimanjaro (Kenya, Tanzania border). In such a context where death was common especially for children, and where large families were expected because of this loss, nevertheless parents exhibited some signs of daily recall. This was despite the fact that they did not

have information such as birthdays, Christmas day, holidays and anniversaries to play upon their minds in their grief. This was influenced by the fact that the burial of the child would be very close to the home, thus being a daily reminder. However other factors such as the way the children were named daily reminded the parents. The African parents, however, did not show the same level of grieving as the English sample with parents showing little or no emotional reaction within the interview. The African context had a belief system that allowed the 'living dead' to be acknowledged and recognised as being close to the bereaved. Yet despite this the community generally attempted not to talk about the loss thus isolating the bereaved in a similar way to in England. Even the Masai who chose not to talk about their loss within their community, exhibited suppressed emotions when allowed to face the issue. The very fact that the Masai dress in a particular way to honour the dead reveals a degree of affiliation with the dead. If 'shadow grief' was present in the African context, then it was not revealed to the same extent as in the English sample. Further research would need to be carried out in a non-western community where a better understanding had been gained of the cultural influences, and a more effective way of communicating could be carried out.

In regards to the loss of children generally, what is needed is a broader framework for looking at the concept of grief. Boro et al (1996) rightly suggests that we need to be including issues such as gender, power, sex orientation and other social differences. It is assumed that emotional distress is an inevitable psychological reaction to the

involuntary breaking of attachments. Bowlby offers us understanding that relationships provide the basis for the growth of independence. The ability to be alone, to be secure with one's own sense of identity rests in large part upon the quality and security of early relationships. Individuals learn as infants how to view the world. Parents who create insecure attachments are those who reject the child's need for reassurance or convey the world as a threatening place as if one can't survive without the parent. This can lead to either emotional coldness or over-dependence on others, a clinging that invites rejection because of its neediness. From this, Parkes (1996) helps us understand the way that parents have the capacity to cope with loss. The concept of psychosocial transitions helps us to see that, with the loss of a child, there is considerably more to lose than with other losses that one may encounter.

The parent-child bond is more than a blood relationship, but consists of a deep emotional tie. The love object is seen as having an unifying affect upon relationships. A child for a parent is a statement of rite of passage, a form of coming of age as an adult. A child also provides a source of power and adult autonomy. This leads to a fulfilment similar to Bowlby's attachment theory of a long lasting affectionate bond. Parents see themselves in their child, whether by the eyes, bodily contour, hair, gender and mannerisms. The child's life becomes a kind of reliving of the parent's own childhood, correcting perhaps the mistakes of their past. This is a projection of self into the child. The child becomes a representation of the future lineage of the family.

The child is also a catalyst to enable the parent to play a role within the local community.

Dependency is therefore not only from the child to the parent but becomes a two way process. The loss of a child is therefore not only the loss of a person but also of oneself as a parent. Despair, particularly with the obsessive rumination of 'why,' is very evident. Indeed various forms of guilt, anger and somatic factors are all evident within the bereaved. It is now finally being recognised that there has been a vast under estimation of the length of time it takes to adjust to the death of a child (Sanders,1999).

It is clear that some parents are better able to express their emotions and that those who find this difficult, perhaps because of the lack of 'open space' which Winnicott (1969) would see as leading to autonomy, can be helped with counselling. Managing the crisis of grief can also help (McLaren,1998). There is also the benefit, as Stroebe and Schut (1995) suggest, of having time off from grief enabling the bereaved time to physically recover at least. However despite all this, it is clear that for many bereaved parents, grief continues to be a part of their lives. The deceased continue to affect the parents such that resolution becomes not one of letting go but of holding on in the light of physical absence. The dead children become a kind of continuing role model. They become a kind of mentor or guide that the parents look to for reassurance. Values and priorities are adjusted in the light of the deceased's previous influence.

The deceased become a significant other in the lives of the bereaved which continue to influence them (Marwit and Klaus,(1995).

It is recognised that there are a range of reactions within parents who lose children.

There are those whose grief fits a normal pattern in which grief factors move from high to lower levels. There are also those who seem to show little sign of high emotional levels of grief. However there are many others interviewed who experience high levels of grief for longer than expected periods, lasting for years. For some, there is a struggle to re-order their reality to accommodate something that did not previously fit with their understanding of the world. The factors that influence a parent in their grief are multiple. The age of the parent, the quality of the relationship prior to loss (with the child as well as the family unit), the perceived uniqueness of the relationship, the cause of death, the anticipation of the loss, the ability to be open to communication, the role the deceased played in giving identity, the interpretation of the loss, the reaction of the community, and varying circumstances post death all influence the direction that grief will take. We know that the pain of the loss can obscure what is taking place within other relationships and Nadeau (1998) has shown that misunderstandings and deep resentments can result.

There is also the confusing role of modern fathers who previously were far less involved with the upbringing of the child. Today the father is often present for the birth and places a greater role in the time he spends with the child. Yet he still carries

the overtones of the masculine provider and protector. The death of the child challenges the role of protector and yet, as Lupton and Barclay (1997) recognise, the loss also reconfirms this role in relation to holding the family together. However this holding together of the family is complicated due to the differing ways a couple may exhibit their grief.

For mothers, the loss challenges their fundamental identity. The physical sharing of the body with the growing foetus, breast feeding, intimate care of the child, and the change of role that the mother experiences within the local community, all heighten the feeling of failure when death occurs. Lupton and Barclay suggest these are all learned skills, but it is more likely that a degree of evolutionary development lie underneath these reactions. The evolutionary roles of protector and carer are radically challenged when loss occurs. Hence, however much the parent seeks to rationalise their behaviour and feelings, it appears to be an emotional reaction that is behind their control. Sims (1997) is right with the view that the dead child is not lost. The bereaved find themselves exploring a landscape that is new and strange. This is the reason that parents need support, encouragement and those around them that are familiar with the strange environment. Hence the benefits of self help groups such as Compassionate Friends. Grief is also complicated further due to various social factors. The decrease of religion, diversity within the community, increasing cultural diversity, increasing geographical mobility, fragmentation of society and saturation of information by the media all leave the bereaved parent more isolated and confused. In

the end, resolution for the parent will depend upon how much the bereaved relied upon the deceased child to mark the boundaries of the survivor's own life. This is why the loss of an older child seems to leave the parent resourceless to bring order and purpose to their lives.

It has now been recognised that due to the increasing multicultural development of society, along with the continuing change of lifestyle that leads to an increasingly anonymous existence and the growing range of contradictory views from experts and media, that there is a growing individualised experience of grief within the bereaved (Riches and Dawson, 2000).

The conclusions of this research are that parents experience over many years, a long lasting grief reaction which focuses upon an intimate loneliness and ongoing rumination which affects their every day lifestyle. This was particularly present in the English context. The loss embraces and challenges the meaning of life, emotional satisfaction, a sense of self worth, the benefits of friendships, partners, a sense of purpose, and what is taken for granted as 'normalness.' The 'life space' that the deceased played remains vacant. This is only partially filled by a sense that the deceased is somehow still with the parent, whether it be through a spiritual view or through taking on the child's perspective of life, or by carrying the mantle of correcting this injustice.

If secure attachment provides a basis for developing a stable, autonomous identity, then one would expect the loss of a sibling to upset the security of a child and postpone a sense of autonomy. The erratic nature of parents, their neglect and over-protection of the surviving sibling all add to the confusion. In addition, the loss of a child also challenges the security of parents. The loss undermines the parent's security in his or her attachment to both partner and to the models that the parent learned as a child. The role model of parents is one of showing and exhibiting to one's child how to be a parent. Models of attachment and affection are fundamentally challenged by the loss of the child. This seems to be affected by the cultural background but to what extent is unclear.

If parents are going to exhibit long term problems with the loss of a child, then those who support and counsel them need to have a realistic map of how to provide support. Bowlby (1979) is right when he suggests that a breadth of relationships helps a person's role of identity. However the idea of detachment as being a precursor to moving on from grief seems less likely. Klass et al's (1996) views of developing more of a 'presence of mind' is more realistic for the bereaved parent who can translate the physical presence of the deceased into an abstract one which journeys with the bereaved and continues to influence and affect the parent right up to their own death. There is the need for a breadth of helpers to assist the parent with their journey. Hospital workers, clergy, family, friends and particularly new friends along with

others who have lost a child can all play their part. Parkes (1996) calls this a spectrum of support.

In the short term, there is the need for helpers to simply be there with the bereaved without having to give answers but rather to share in the right to ask questions which have no answers. Giving opportunity to tell the story which is more expected in other cultures, is very beneficial to the bereaved. There is the need to go on telling the story until parents choose to stop. There is already a recognised acceptance that the bereaved need to express their shock, hurt, anger, and to search for their loss in their own way. This is no different to other losses. However in time, parents begin to particularly look for answers in a way that is different from their initial questioning. In the beginning of the loss parents are simply asking the questions without wanting answers. Any answer at an early stage will be inadequate, but as the months go on parents want to begin to work out in their own mind why they have experienced this loss. For many, no answer is ever sufficient. Others find some consolation in spiritual conclusions ('I know he is somewhere special'), nihilistic conclusions ('it's all a mess') and survival conclusions ('life goes on'). The finding of someone to assist with this search is important to the parent to feel that they are not alone. Alas often the carers have lost touch with the bereaved by this stage. The desire to seek spiritualists etc. is common but seems to be a temporary help. It is important that parents are respected for whatever views they finally formulate.

The role of possessions, dreams, and special places all play a part in comforting the bereaved. In the past these have sometimes been seen to be negative factors, however parents generally view these components as helpful. Hospitals now see the benefit of 'treasure boxes,' and this is no different to parents who maintain a presence in the home of the deceased's possessions. To gain understanding of these factors, parents will often find benefit in meeting with others who are also trying to cope with their loss. This is where Compassionate Friends and other self help groups can be so supportive. There is a greater degree of stickability with friends who have experienced similar losses. However there is also the danger that a parent might get caught within the organisation such that they feel unable to one day move on from the group. Similarly the danger exists that by continuing to focus upon the loss, some parents may exhibit high levels of grieving that may be pathological and require intervention.

Parents seem to come to a more balanced lifestyle when they are at peace with the fact that the deceased will continue to influence their lives. Being able to locate the deceased within ones life such that one can continue to function within a family, work and community is a positive resolution.

There needs to be a recognition that there are a variety of reactions to the loss of a child. The more a community can recognise that fathers, mothers, and siblings may well react with a variety of emotions that are different to each other, the less pressure will be exhorting upon the family unit. It is recognised that in the grief journey many

will experience intense suicidal feelings. These feelings may persist for a considerable time, however for most the basic survival instinct will remain.

In the end what is required is an open minded multi-dimensional view of support which recognises the depth of damage that the loss of a child creates, and the slow process of healing which in the end may not be completed within the parent's lifetime.

CHAPTER 9

BIBLIOGRAPHY

ADLER, A. Neuropsychiatric complications in victims of Boston's coconut grove disaster. *Journal of American Medical Association*, 1943, 123, pp.1098-1101.

AIKEN, L. *Dying, death, and bereavement*. Rockleigh, New Jersey: Allyn & Bacon. 1985.

AINSWORTH, D. & WITTIG, B. Attachment and exploratory behaviour of one-year olds in a strange situation. In FOSS, B. (ed.). *Determinants of Infant behaviour*, London: Methuen, vol 4, 1969.

AINSWORTH, M. Object relations, dependency, & attachment: a theoretical review of infant-mother relationship. *Child Development*, 1968, 40, pp.969-1025.

AINSWORTH, M. Attachments and other affectional bonds across the life cycle. In PARKES, C. M. STEVENSON-HINDE, J. & MARRIS, P. *Attachment across the life cycle*, London: Routledge, 1991.

ALTSCHUL, S. (ed.). *Childhood Bereavement and its aftermath*. New York: International University Press, 1988.

AMERICAN PSYCHIATRIC ASSOCIATION: *Diagnostic and Statistical Manual of Mental Disorders*. Fourth Edition, International Version. Washington, DC. 1995

ARCHER, J. *The nature of grief: The evolutionary and psychology of reactions to grief*. London: Routledge, 1999.

ARMSTRONG-DAILEY, A. & GOLTZER, S. Z. (ed.). *Hospice Care for Children*, New York: Oxford Press, 1993.

BALK, D. The self-concepts of bereaved adolescents: Sibling death and its aftermath. *Journal of Adolescent Research*, 1990, 5, pp.112-132.

BARTLETT, D. *Stress*. Buckingham: Open University Press, 1998.

BELSKY, J. & ROVINE, M. Temperament and attachment security in the strange situation: an empirical rapprochement. *Child Development*, 1987, 58, pp.787-795.

BENEDEK, T. Parenthood as a developmental phase. *American Psychoanalytic Association Journal*, 1959, 7, pp.389-417.

BERGER, A. Quoth the raven: bereavement and the paranormal. *Omega, Journal of Death and Dying*, 1995, 31, pp.1-10.

BERTI, G. When an offspring dies: logotherapy in bereavement groups. *International Forum for Logotherapy*, 1994, 17, pp.65-69.

BIRINGEN, Z. Attachment theory and research. *American Journal of Orthopsychiatry*, 1994, July, 64, pp.404-420.

BLACH, H. Sudden, unexpected pediatric death. *Pediatric Nursing*, 1991, 17, pp.571-575.

BOER, F. & DUNN, J. (eds). *Children's Sibling Relationships: Developmental and Clinical Issues*. New Jersey: Lawrence Erlbaum Assoc. 1992.

BOR, R., LEGG, C. & SCHER, I. The systems paradigm. In WOOLFE & DRYDEN, W. (eds). *Handbook of Counselling Psychology*, London: Sage, 1996.

BORG, S. & LASKER, J. When pregnancy fails, Coping with miscarriage, stillbirth and infant death. London: Routledge & Kegan Paul, 1982.

BOWLBY, J. *Attachment & loss*, vol.1, *Attachment*. New York: Basic Books, 1969.

BOWLBY, J. *Attachment & loss*, vol.2, *Seperation, anxiety and anger*. New York: Basic Books, 1973.

BOWLBY, J. *Attachment & loss*, vol.3, *Sadness and depression*. New York: Basic Books, 1980.

BRABANT, S. & MART, L. Parental bereavement in anglo-american history. *Omega, Journal of Death and Dying*. 1993. 28 (1) pp49-61.

BRABANT, S., FORSYTH, C. & McFARLAIN, G. Life after the death of a child: Initial and long term support from others. *Omega, Journal of Death and Dying*, 1995, 31, pp.67-85.

BRADACH, K. & JORDAN, J. Long-term effects of a family history of traumatic death on adolescent individuation. *Death Studies*, 1995, 19, pp.315-336.

- BRETHERTON, I. The Origins of attachment theory: John Bowlby and Mary Ainsworth. *Developmental Psychology*, 1992, 28, pp.759-775.
- BRYANT, C. Fathers grieve too. *Journal of Perinatology*, 1989, 9, pp.437-441.
- BYNG-HALL, J. Evolving ideas about narrative: Re-editing of the family mythology. *Journal of Family Therapy*, 1998, 20, pp.133-141.
- CAMERON, N. *Personality development and psychopathology, a dynamic approach*, New York: Houghton Mifflin, 1963.
- CANNON, W. *Bodily changes in pain, hunger, fear and rage*. London: Appleton, 1929.
- CHANG, E. C., ASAKAWA, K. & SAMA, L. J. Cultural variations in optimistic and pessimistic bias. *Journal of Personality and Social Psychology*, 2001, 81, 476-491.
- CHARLES-EDWARDS, D. *Bereavement at work*. London: Duckworth. 2000.
- CHADOFF, P., FRIEDMAN, S., & HAMBURG, D. Stress, defense and coping behaviour: Observations in parents of children with malignant disease. *American Journal of Psychiatry*. 1964, 120, pp.743-749.
- CLARK, S. & GOLDNEY, R. Grief reactions and recovery in a support groups for people bereaved by suicide. *Crisis*, 1995, 16, pp.27-33.
- CASSEM, N. Bereavement as indispensable for growth. In SCHEONBEZ, B. et al (ed). *Bereavement : Its Psychosocial Aspects*. New York: Columbia Press, 1975.
- CLAYTON, P., DESMARAIS, L. & WINOKUR, G. A study of normal bereavement. *American Journal of Psychiatry*, 1968, 125, pp.47-51.
- CLERICO, A. Behaviour after cancer death in offspring. *New Trends in Experimental and Clinical Psychiatry*, 1995, 11, pp.87-89.
- CLYMAN, R. et al, Issues concerning parents after the death of their newborn. *Critical Care Medicine*, 1980, 8, pp. 215-218.
- COHEN, R. The death of an adult child, acute grief, and a closure to parenting. In MARGOLIS, O. et al. *Grief and the loss of an adult child*. New York: Praeger. 1988,

CONRAD, R. *When a child has been murdered: Ways you can help the grieving parents*. Amityville: New York, 1998.

COOKE, J. A Death in the family: suicide & life. *Threatening Behaviour*, 1983, 13, pp. 42-61.

CORR, C. & CORR, D. *Handbook of childhood death and bereavement*. New York: Springer, 1996.

COX, G, FUNDIS, R (ed.). *Spiritual, ethical and pastoral aspects of death and bereavement*. New York: Baywood, 1992.

CRITTENDEN, P. M. The effect of mandatory protective daycare on mutual attachment in maltreating mother-infant dyads. *Child Abuse and Neglect*, 1983, 7.

CROOKS, P. *Lebanon: The pain and the glory*. Eastbourne: Monarch, 1990.

CUISINIER, M., JANSSEN, H., dE GRAAUW, C., BAKKER, S. & HOOGDUIN, C. Pregnancy following miscarriage: course of grief and some determining factors. *Journal of Psychosomatic Obstetrics and Gynecology*. 1996, 17, pp.168-174.

DEITS, B. *Life after loss: A personal guide dealing with death, divorce, job change and relocation*. Tuscon: Fisher Books, 1992.

DE MAUSE, L. The evolution of childhood. *History of Childhood Quarterly*, 1974, 1, pp.504-575.

DE MASO, D., MEYER, E., & BEASLEY, P. What do I say to my surviving children? *Journal of the American Academy of Child and Adolescent Psychiatry*, 1997, 36, pp.1299-1302.

DE VRIES, B. Parental bereavement over the life course. *Omega, Journal of Death and Dying*, 1994, 29, pp.469-470.

DICKENSON, D. & JOHNSON, M. (eds.). *Death, dying & bereavement*. London: Sage Publishing, 1993.

DOKA, K. & JENDRESKI, M. Spiritual support for the suffering: Clergy attitudes towards bereavement. *Loss, Grief and Care*, 1986, 1, pp.155-160. .

DOKA, K. *Disenfranchised grief - Recognising hidden sorrow*. New York: Lexington Books, 1989.

DRENOVSKY, C. Anger and the desire for retribution among bereaved parents. *Omega, Journal of Death and Dying*, 1994, 29, pp.303-312.

DUCK, S. *Meaningful relationships - Talking, sense & relating*. London: Sage, 1994.

DYREGROV, A. *Grief in children, a handbook for adults*. London: Jessica Kingsley, 1991.

DYREGROV, A & MATTHIESEN, S. Parental grief following over one year. *Scandinavian Journal of Psychology*, 1991, 32, pp.193-207.

ENGEL, G.L. Grief and Griving. *American Journal of Nursing*, 1964, 9, pp.93-98.

FARRANT, A. *Sibling bereavemnt: Helping children cope with loss*. London: Cassell, 1998.

FEENEY, J. & NOLLER, P. *Adult attachment*. London: Sage, 1996.

FEIFEL, H. Grief and bereavement. *Bereavement Care*, 1998, 7, pp.2-4.

FINKBEINER, A. *After the death of a child - Living with loss through the years*. Baltimore: John Hopkins University Press, 1996, p. xiii.

FISH, W. Differences of grief intensity in bereaved parents. In RANDO, T. (ed.). *Parental loss of a Child*. Illinois: Champaign Research Press, 1986, pp.415-428.

FORTE, J., BARRETT, A., & CAMPBELL, M. Patterns of social connectedness and shared grief work: A symolic interactionist perspective. *Social Work with groups*, 1996, 19, pp.29-51.

FREUD, E. (ed.). *Letters of S. Freud*. New York: Basic Books, 1960.

FREUD, S. *Thoughts for the times on war and death*. Vol 14 of the Standard Edition of the Complete Psychological Works of Sigmund Freud. Toronto: Hogarth, 1957.

FREUD, S. *Mourning and Melancholia*. New York: Basic Books, 1959, vol.4. (Standard edition in 1917)

FREUD, S. Mourning & melancholia. In STRACHEY, J. (ed.). *The Standard Edition of The Complete Psychological works of S. Freud*. London: Hogarth Press, 1961, vol. 14, p.239.

FREUD, S. *Totem and taboo*. London: Routledge and Keegan Paul, 1983.

FOLTA, J. R. & DEECK, E. S. " The impact of children's death on Shona mothers and families." *Journal of Comparative Family Studies*, 1988, 19, p.433-451.

FUTTERMAN, E. & HOFFMAN, I. Crisis & adoption in families of fatally ill children. In Anthony, E. & Koupernik, C. (ed.). *The Child & His Family*, New York: John Wiley & Sons, 1973, vol. 12.

FURMAN, E. Caring for the parents of an infant who dies. In KENNEL, J. & KLAUS, M. *Maternal-Infant Bonding*, St Louis: Cumosby CO., 1976. pp. 233-235.

GENTRY, J. & GOODWIN, C. Social support for decision making during grief due to death. *American Behavioural Scientist*, 1995, 38, pp.553-563.

GERMEET, S. Acute Grief: The first year of bereavement. *Indian Journal of Psychiatry*, 1989, 31, pp.187-95.

GERSIE, A. *Story making in bereavement*. London: Jessica Kingsley, 1991.

GILBERT, K. We've had the same loss, why don't we have the same grief? loss and differential grief in families. *Death Studies*, 1991.20(3). pp.269-283.

GILBERT, K. & SMART, L. *Coping with infant or fetal loss: the couple's healing process*. New York: Brunner & Mazel, 1992.

GILMOUR, D. *Lebanon: The fractured country*. London: Sphere Books, 1983.

GLASCOCK, A. P. & BRADEN, R. W. *Transitionals of being: death and dying in cross-cultural perspective*. (unpublished paper presented at the annual meeting of the American Anthropological Association, Los Angeles, Dec. 1981). Cited in PARKES, C. M., LAUNGANI, L. & YOUNG, B. *Death and Bereavement Across Cultures*. London: Routledge, 1997.

GLICK, I., WEISS, R., & PARKES, C. *The first year of bereavement*. New York: John Wiley, 1974.

GOLDBERG, S., MUIR, R. & KERR, J. (eds.). *Attachment theory: Social, developmental, and clinical perspectives*. Hillsdale: The Analytical Press, 1995.

- GOTAY, C. Cultural variations in family adjustment to cancer, in Baider, L., Cooper, C. and De-Nour, A. (ed.s) *Cancer and the Family*. Chester: John Wiley and Sons. 1996.
- GORDON, J. Grieving together, in SMITH, S. AND PENNELLS, M. *Interventions with Bereaved Children*. London: Jessica Kingsley. 1995.
- GORER, G;. *Death, Grief & Mourning*, London: Cresset Press.1965.
- HAGMAN, G. Mourning: A Review and Reconsideration. *International Journal of Psychoanalysis*, 1995, 76, pp.909-925.
- HRDY, S. *The woman that never evolved*. Cambridge, Harvard press: 1981.
- HART, B. The construction of the gendered self. *Journal of family Therapy*, 1996, 18, pp.43-60.
- HARVEY, J. *Perspectives on Loss*. Philadelphia: Brunner & Mazer, 1998.
- HAZZARD, A. After a child's death: factors related to parental bereavement. *Journal of Developmental & Behavioural Pediatrics*, 1992, 13, pp 24.-30.
- HINDE, R. & STEVENSON-HINDE, J. Implications of a relationships approach for the study of gender differences. *Infant Mental Health Journal*, 1987, 8, pp.221-236.
- HINDMARCH, C. Secondary losses for siblings. *Child: Care, Health and Development*, 1995, 21, pp.425-431.
- HOCKER, W. Parental loss of an adult child. In MARGOLIS, O. et al. *Grief and the loss of an adult child*. New York: Praeger, 1988.
- HOGAN, N. & DESANTIS, L. Adolescent sibling bereavement: an ongoing attachment. *Qualitative Health Research*, 1992, 2, pp. 159-177.
- HOGAN, N. & DESANTIS, L. Things that help and hinder adolescent sibling bereavement. *Western Journal of Nursing Research*, 1994, 16, pp.132-153.
- HOGAN, N. & DESANTIS, L. Adolescent sibling bereavement: towards a new theory. In CORR. C. & BALD. D. (eds.). *Handbook of Adolescent Death and Bereavement*. New York: Springer, 1996.
- HOROWITZ, M., SIEGEL, B., HOLEN, A., BONNANO, G., MILBRATH, C., & STINSON, C. Diagnosis criteria for complicated grief disorder. *American Journal of Psychiatry*, 1997, 154, pp.904-910.

HORTON, P. *Solace, the missing dimension in psychiatry*. Chicago: University of Chicago Press, 1981.

IRONSON, G., WYNINGS, C., AND SCHNEIDERMAN, N. Posttraumatic stress symptoms, intrusive thoughts, loss and immune function after hurricane Andrew: *Psychosomatic Medicine*, 1997, 59, pp.128-141.

JACKSON, E. *Understanding Grief*. Nashville: Abingdon Press, 1957.

JACKSON, E. in Linzer (ed.). *Understanding bereavement & grief*. New York: Yeshiva Press, 1977.

JABOBS, S. *Traumatic grief, diagnosis, treatment and prevention*. London: Taylor & Francis, 1999.

JANOFF-BULMAN, R. *Shattered Assumptions: Towards a New Psychology of Trauma*. New York: The Free Press, 1992.

JEFIDOFF, A. Helping the parents of a dying child - An Israeli experience. *Journal of Paediatric Nursing*, 1993, 8, pp. 413-415.

JUNG, C. *Memories, dreams and reflections*. London: Routledge and Kegan Paul, 1963.

JUNG, C. The soul and death. In vol 8 of The collected works of C. G. Jung. London: Routledge and Kegan Paul, 1969.

KALISH, R. (ed.). *Death and dying: a view from many cultures*. New York: Baywood Pub. Co., 1979.

KAPLAN, L. *No voice is ever wholly lost*. New York: Simon & Schuster, 1995.

KAPLAN, T. *Mr. Clemens and Mark Twain*. New York: Simon and Schuster.

KENNEL, J. SLYTER, H. KLAUS, M. The mourning response to the death of a newborn infant in the New England. *Journal Of Medicine*, 1970, vol. 283, pp. 344-349.

KIRCHBERG, T. Beginning counsellor's death concerns and empathic responses to client situations involving death and grief. *Death Studies*, 1998, 22, pp.99-120.

KLAUS, M. & KENNEL, J. Maternal infant bonding. St. Louis: Mosby Press, 1976.

KLASS, D. Bereaved parents and the compassionate friends : affiliation & healing. *Omega, Journal of Death and Dying*, 1984-85, Vol.15, pp. 353-373.

KLASS, D. John Bowlby's model of grief and the problem of identification. *Omega*. 1987-88, 19, pp.13-32.

KLASS, D. *Parental grief: solace and resolution*, New York: Springer Publishing, 1988.

KLASS, D. MARWIT, S. Toward a model of parental grief. *Omega*, 1988-89, 19, pp.31-50.

KLASS, D, SILVERMAN, R. & NICKMAN,L. (ed.). *Continuing bonds*. Washington: Taylor and Francis, 1996.

KLASS, D. Solace and immortality: bereaved parents continuing bond with their children. *Death Studies*, 1993, 17, pp.343-368.

KLIMAN, A. *Understanding Bereavement & Grief*. New York: Yeshiva Press. 1977.

KNAPP, R. *Beyond endurance*. New York: Schochen, 1986.

KOOCHER, G. & O'MALLERY, J. *The damocles syndrome*. New York: McGraw-Hill,1981.

KUBLER-ROSS, E. *On death & dying*. London: Tavistock, 1970.

KUBLER-ROSS, E. *On children and death*. New York:Collier, 1983.

LANG, A. GOTTLIEB, L. & AMSEL, R. Predictors of husbands and wives grief reactions following infant death: the role of marital intimacy. *Death Studies*, 1996, 20, pp.33-57.

LANTZ, J. & AHERN, R. Re-collection in existential therapy with couples and families facing death. *Contemporary Family Therapy: An International Journal*, 1998, 20, pp.47-57.

LAUNGANI, P. Death and bereavement in India and England: a comparative analysis. *Mortality*. 1996, 1, pp.191-212.

LAWICK-GOODALL VAN, J. *In the shadow of man*. Boston: Houghton Mifflin, 1971.

LAZARE, A. *Unresolved grief in outpatient psychiatry: diagnosis and treatment*. Baltimore: Wilcombe & Wilkins, 1979.

LEGGE, C. & SHERICK, I. The replacement child. *Psychiatry & Human Development*, 1976, vol. 7, pp.113-127.

LEMING, M. & DICKINSON, G. *Understanding dying, death and bereavement*. Orlando: Harcourt Brace College Publications, 1985.

LEVINE, C. Orphans of the HIV epidemic. *Aids Care*. 1995, Feb. 1, pp.57-62.

LEWIS, C. S. *A grief observed*. London: Faber. 1961.

LINDEMANN, E. The Symptomatology and management of acute grief. *American Journal of Psychiatry*, 1944, pp.101-141.

LINDEMANN, E. Symptomatology & management Of acute grief. In Papad, J. (ed.). *Crisis intervention, selected readings*. New York:Family Service Assoc. of America. 1978.

LITTLEFIELD, C. & RUSHTON, J. When a child dies: the sociobiology of bereavement. *Journal of Personality and Social Psychology*. 1986, 51, pp.797-802.

LITTLEWOOD, J. *Aspects of grief*. London: Tavistock, 1992.

LIVNEH, H. ANTONAK, R. MARON, S. Progeria:medical aspects, psychosocial perspectives, and intervention guidelines. *Death Studies*, 1995,19, pp.433-452.

LUPTON, D. & BARCLAY, L. *Constructing fatherhood: discourses and experiences*. London: Sage, 1997.

LYNCH, J. Tthe broken heart: medical consequences of loneliness. In MARGOLIS, O. et. al. *Grief and the loss of an adult child*. New York.Praeger, 1988.

MABE, P. & DAWES, M. When A child dies. *Journal of Psychology & Theology*, 1991, vol.19, pp.334-343.

MAHAN, C. & CALICA, J. Perinatal loss: considerations in social work practice. *Social Work in Health Care*, 1997, 24, pp.141-152.

- MAIN, M., KAPLAN, K., & CASSIDY, J. Security in infancy, childhood and adulthood: a move to the level of representation. In BRETHERTON, I. & WATERS, E. (eds.). Growing points of attachment theory and research. *Monographs of the Society for Research in Child Development*. 1985. 209.
- MARRIS, P. *Widows & Their Families*. London: Routledge & Kegan Paul. 1958.
- MARRIS, P. Grief, loss of meaning and society. *Bereavement Care*. 1992, 11, pp.18-23.
- MARSHALL, C. et. al. *Designing Qualitative Research*. London: Sage Publications. 1989.
- MARTINSON, I. Grief is an Individual Journey: Follow-up of Families Postdeath of a Child with Cancer, in PAPADATOU, D. & PAPADATOU, C. (eds) *Children and Death*. New York, Hemisphere.1991.
- MARTINSON, I. & Mc.CLOWRY,S. Change over Time - Study of Family Bereavement Following Childhood Cancer. *Journal of Palliative Care*,1994. 10, pp.19-25.
- MARTINSON, I. DAVIS, B. & McCLOWRY, S. Parental depression following the death of a child. *Death Studies*, 1991,15, pp.259-267.
- Mc.COWN, D. Patterns of grief in young children following the death of a sibling. *Death Studies*, 1995,19, pp.41-53.
- McCLOWRY, S. G., DAVIES, E. B., MAY, K. A., LULENKAMP, E. J. & MATINSON, I. M. The empty space phenomenon: the process of grief in the bereaved family. *Death Studies*, 1987, 11, p.361-374.
- McGOLDRICK, M. & WALSH, F. *Living beyond loss: death in the family*. New York: Norton. 1991.
- McGREAL, D., EVANS, B. & BURROWS, G. Gender differences in coping following loss of a child through miscarriage or stillbirth.: a pilot study. *Stress Medicine*, 1997, 13, pp.159-165.
- McLAREN, L. A new understanding of grief: a counsellor's perspective. *Mortality*, 1998, 3, pp.275-290.

MERRINGTON, B. *Bereavement in families who have lost babies, children, teenagers and young adults*. Unpublished M.Phil. dissertation, Birmingham University. 1995.

MERRINGTON, B. *Suffering love: coping with the death of a child*. Leamington Spa: Advantage. 1996.

MERRINGTON, B. *The hideaway: a book for children who grieve*. Bury St. Edmunds: Kevin Mayhew. 1998.

MERRINGTON, B. *Alice's dad: a book for children who grieve*. Bury St. Edmunds: Kevin Mayhew. 1999.

MIDDLETON, W., RAPHAEL, B., BURNETT, P. & MARTINEK, N. A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. *Australian and New Zealand Journal of Psychiatry*, 1998, 32, pp.235-241.

MOGENSON, G. *Spiritual, ethical & pastoral aspects of death & bereavement*. New York: Baywood. 1992.

MONTADA, L., FILIPP, S., & LERNER, M. (eds.). *Life crises and experiences of loss in adulthood*. New Jersey: Lawrence, Erlbaum Associates. 1992.

MOOREY, J. *Living with grief & mourning*. Manchester: Manchester Press. 1995.

MOSS, M. LESHER, E. & MOSS, S. Impact of the death of an adult child on elderly parents: some observations. *Omega, Journal of Death and Dying* 1986-7, 17, pp.209-218.

MURPHY, S. A theory based preventive intervention program for bereaved parents whose children have died in accidents. *Journal of Traumatic Stress*, 1989, 2, pp.319-334.

NADEAU, J. *Families making sense of death dysfunction*. Thousand Oaks: Sage. 1997.

NEIDIG, J. Parental grieving and perceptions regarding health care professionals. *Issues in Comprehensive Pediatric Nursing*, 1991, 14, pp.179-191.

NEUBAUER, R. Association for marriage & family therapy. In DONNELLY, K. *Recovering From The Loss Of A Child*. New York: Macmillan. 1982.

- NOLEN-HOEKSEMA, S., PARKER, L. & LARSON, J. Rumination coping with depressed mood following loss. *Journal of Personality and Social Psychology*. 1994, 67, pp.92-104.
- OKAFOR, T Death education in The Nigerian hme: the mother's role. *Omega, Journal of Death and Dying*, 1993, 27, pp.271-280.
- PAPADATOU, D. & PAPADATOS, C. *Children and death*. New York: Hemisphere.1991.
- PARKES, C. M. Determinants of outcome following bereavement. *Omega, Journal of Death and Dying* 1975, 6, pp 303-23.
- PARKES, C. M. *Bereavement studies of grief in adult life*. London: Tavistock. 1972.
- PARKES, C. M. & WEISS, R. S. *Recovery from bereavement*. New York: Basic Books. 1983.
- PARKES, C. M. *Bereavement studies of grief in adult life*. London: Penguin. 1986.
- PARKES, C. M., STEVENSON - HINDE, J. & MARRIS, P. Attachment across the life cycle. London: Routledge.1991.
- PARKES, C. M., LAUNGANI, L. & YOUNG, B. *Death and bereavement across cultures*. London:Routledge.1997.
- PAYNE, J. GOTT, J. & PAULSON, M. Psychosocial adjustment of families following the death of a child. In SHULMAN, J. & KUPSE, M (eds.). *The child with cancer*. Springfield Illonois: Charles C. Thomas. 1980.
- PAYNE, S., HORNE, S., AND RELF, M. *Loss and bereavement*. Buckingham: Open University Press. 1999.
- PEARN, J. Emotional sequelae of parents & siblings following the drowning or near drowning of a child. *Australian & New Zealand Journal of Psychiatry*, 1977, 11, pp. 265-268 .
- PENNEBAKER, J. *Opening up: The healing power of confiding in others*. New York: Morrow.1990.
- PEPPERS, L. & KNAPP, R. *Motherhood and mourning: perinatal death*. New York: Prager. 1980.

- PERRY, H. L. Mourning and funeral customs of african americans. In IRISH, D.P., LUNDQUIST, K. F. & NELSON, V. J. (eds.). *Ethnic variations in dying, death and grief*. London: Taylor & Francis. 1993.
- PETERSON, G. & MAHL, L. Some determinants of maternal attachment. *American Journal of Psychiatry*, 1978,135, pp.1168-1173.
- PETTLE, S. & BRITTEN, C. Talking with children about death and dying. *Child: Care, Health and Development*, 1995, 21, pp. 395-404.
- PONZETTI, J. The forgotten grievers. *Death Studies*, 1991. p.15.
- POWELL, M. The psychosocial impact of sudden infant death syndrome & siblings. *The Irish Journal of Psychology*, 1991, 12, pp.235-247.
- PRICHARD, S. Children and death : new horizons in the theory and measurement. *Omega, Journal of Death and Dying*, 1991, 24, pp.271-288.
- PRIGERSON, H., MACIEJEWSKI, P., NEWSOM, J., REYNOLDS, C., FRANK, E., BIERHALS, A., MILLER, M., FASICZKA, A., DOMAN, J., & HOUCK, P. The inventory of complicated grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Research*, 1995, 59, pp.65-79.
- PRONG, L. Childhood bereavement among cambodians: cultural considerations. *Hospice Care*, 1995, 10, pp.51-64.
- PUDDIFOOT, J. & JOHNSON, M. The legitimacy of grieving: the partner's experience at miscarriage. *Social Science And Medicine*, 1997, 45, pp.837-845.
- RANDO, T. An investigation of grief and adaption in parents whose children have died from cancer. *Journal of Paediatric Psychology*, 1983, vol.8, pp. 3-19.
- RANDO, T. Bereaved parents : particular difficulties, unique factors & treatment used. *Social Work*, 1985, pp.19-23.
- RANDO, T. An investigation of grief and adaption in parents whose children have died from cancer. *Journal of Pediatric Pyschology*, 1983, 8, pp.3-20.
- RANDO, T. *Introduction in parental loss of a child*. Illinios:Research Press. 1986.

RANDO, T. *Parental loss of a child*. Illinois: Research Press. 1986.

RANDO, T. Parental adjustment to the loss of a child. In PAPADATOU, D. PAPADATOS, C. (eds.). *Children and Death*. New York: Hemisphere.1991.

RAPHAEL, B. *The anatomy of bereavement*. London: Hutchinson.1984,

REES, D. The hallucinations of widowhood. *British Medical Journal*, 1971, 4, pp.37-41.

REES, D. *Death and bereavement, the psychological, religious and cultural interfaces*. London: Whurr. 1997.

REIF, L Bereavement, stress and social support in members of a self help group. *Journal of Community Psychology*, 1995, 23 pp.292-306.

RICHES, G. & DAWSON, P. *An intimate loneliness - supporting bereaved parents and siblings*. Buckingham: Open University Press. 2000.

ROBINSON, L. & MAHON, M. Sibling bereavement: a concept analysis. *Death Studies*, 1997, 21, pp.477-499.

ROGERS, R. & MAN, J. *Reaching for the children*. London: Arrow Books. 1990.

ROSENBLATT, P., SIEGEL, H. & MEYER, A. Progress in the study of maternal behaviour in the rat: hormonal, non-hormonal, sensory, and developmental aspects. In ROSENBLATT, R. et. al. (eds.). *Advances in the study of behaviour*. New York: Academic Press. 1979, vol.10, pp.225-311 .

ROSENBLATT, P. Grief that does not end. In KLASS, D., SILVERMAN, R. & NICKMAN, S. (eds.). *Continuing bonds: new understandings of grief*. Washington, DC: Taylor & Francis. 1996.

ROSENBLATT, P. Grief in small societies. In PARKES, C. M. LAUNGANI, L. & YOUNG, B. *Death and Bereavement Across Cultures*. London:Routledge. 1997.

ROSENBLATT, R. C., WALSH, R.P. & JACKSON, D.A. *Grief and mourning in cross-cultural perspective*. Washington DC: HRAF Press. 1976.

ROSKIN, M. Emotional reaction among bereaved israeli parents. *Israeli Journal of Psychiatry & Related Sciences*, 1984, 21, pp. 73-84.

- RUBIN, S. The wounded family: bereaved parents and the impact of adult child loss. In KCLASS, D., SILVERMAN, R. & NICKMAN, S. (eds.). *Continuing bonds: new understandings of grief*. Washington, DC: Taylor & Francis. 1996.
- RUBIN, S. Death of the future: An outcome study of bereaved parents in Israel. *Omega, Journal of Death and Dying*, 1989, 20, pp.323-339.
- RUBIN, S. The Death of a child is forever: the life course impact of child loss. In STROEBE, M., STROEBE, W. & HANSSON, R. (eds.). *Handbook of bereavement, theory, research and intervention*. New York: Cambridge University Press.
- SANDERS, C. A comparison of adult bereavement in the death of a spouse, child and parent. *Omega, Journal of Death and Dying*, 1979-80, 10, pp. 303-322.
- SANDERS, C. *Grief The mourning after*. New York: John Wiley & Co. 1999.
- SANDLER, I. Linking empirically based theory and evaluation: the family bereavement program. *American Journal of Community Psychology*, 1992, 20, pp. 491-521.
- SCHATZ, B. Grief of fathers. In RANDO, T.(ed.) *Parental loss of a child*. Illinois: Research Press. 1986.pp.303-314.
- SCHEPER-HUGHES, N. *Death without weeping: The violence of everyday life in Brazil*.Berkeley: University of California Press. 1992.
- SCHIFF, H. The bereaved parent. New York: Crown. 1977.
- SCHNEIDERMAN, G. WINDERS, P. & TALLETT, S. Child, parent bereavement programmes. *Canadian Journal of Psychiatry*, 1994, 39, pp.215-218.
- SCHOR, E. *Bearing the dead, the british culture of mourning from the enlightenment to victoria*. New Jersey: Priceton University Press. 1994.
- SCHWAB, J. et. al. Studies in grief : a preliminary report. In SCHOENBERG, B. et. al. (eds.). *Bereavement : it's psychosocial*. New York: Columbia University Press.1975, pp. 82-87.
- SCHWAB, R. Effect of a child's death on the marital relationship. *Death Studies*, 1992, 16, pp.141-154.
- SCHWAB, R. Bereaved parents and support group participation. *Omega, Journal of Death & Dying*, 1995, 32, pp.49-61.

SCHWAB, R. Gender differences in parental grief. *Death Studies*, 1996, 20, pp.103-114.

SCHWAB, R. Parental mourning and children's behaviour. *Journal of Counselling and Development*, 1997, 75, pp.258-265.

SCHWAB, R. A child's death and divorce: dispelling the myth. *Death Studies*, 1998, 22, pp.445-468.

SCHWARTZ, A. The parents. In LINZER, N. (ed.). *Understanding bereavement & grief*. New York: Yeshiva Press. 1977.

SEGAL, N. Comparative grief experiences of bereaved twins & other relatives. *Personality and Individual Differences*, 1995, 18, pp.511-524.

SELYE, H & HORAVA, A. *Annual reports on stress*. Montreal: Acta Institute, 1950.

SHANE, E. & SHANE, M. Object loss and self object loss: a contribution to understanding mourning and the failure to mourn. *Annual of Psychoanalysis*, 1990, 18, pp.115-131.

SHANFIELD, S., BENJAMIN, G. & SWAIN, B. The family under stress: the death of adult children. In MARGOLIS, O. et. al. *Grief and the loss of an adult child*. New York: Praeger. 1988.

SHERMAN, B. *Parental bereavement & marriage*. Unpublished Phd. Thesis. Chicago University. 1982.

SILVERMANN, P. Parent child communication in bereaved israeli families. *Omega, Journal of Death and Dying*, 1995, 31, pp.275-293.

SIMMS, D. Wallowing. Paper presented at the second international gathering of the Compassionate Friends, Adam's Mark Hotel, Philadelphia. In RICHES, G. & DAWSON, P. *An intimate loneliness - supporting bereaved parents and siblings*. Buckingham: Open University Press. 2000.

SINCLAIR, I. & McCLUSKEY, U. Invasive partners: an exploration of attachment, communication and family patterns. *The Journal of Family Therapy*, 1996, 18, pp.61-78.

SLUCKIN, W. HERBERT, M., & SLUCKIN, A. *maternal bonding*. Oxford: Basil Blackwell. 1983.

- SMART, L. Parental bereavement in anglo- american history. *Omega, Journal of Death and Dying*, 1993, 28, pp.49-61.
- SMITH, S. AND PENNELLS, M. *Interventions with bereaved children*. London: Jessica Kingsley. 1995.
- SMUTS, B. Dynamics of special relationships between adult male and female baboons. In HINDE, R. (ed.). *Primate Social Relationships*. Oxford: Blackwell. 1983, pp.112-116.
- SPINETTA, J. SWARNER, J. & SHEPOSH, J. Effective parental coping following the death of a child from cancer. *Journal of Paediatric Psychology*, 1981, 6, pp. 251-263.
- STAHL, A. Parents attitudes towards the death of infants in the traditional jewish oriental family. *Journal of Comparative Family Studies*, 1991, 22, pp.75-83.
- STAHLMAN, S. Children and the death of a sibling. In CORR, A. & CORR, D. (eds.). *Handbook of Childhood Bereavement*. New York: Springer. 1996.
- STAUDACHER, C. *Beyond Grief*. London: Souvenir Press. 1987.
- STEELE, B. Psychodynamic factors in child abuse. In KEMPE, C. & HELFER, R. the battered child. Chicago: University of Chicago Press. 1980.
- STEELE, D. The bereaved merit special attention. In MARGOLIS, O. et al. *Grief and the loss of an adult child*. New York: Praeger. 1988.
- STERN, D. *The First relationship: infant and mother*. London: Open Books. 1977.
- STEWART, R. Sibling attachment relationship: child - infant interactions in the strange situation. *Developmental Psychology*, 1983, 19, pp.192-199.
- STOKES, J., WYER, S., & CROSSLEY, D. The challenge of evaluating a child bereavement programme. *Palliative Medicine*, 1997, 11, pp. 179-90.
- STONE, L. *The family, sex and marriage, 1500-1800*. Abridged edition. New York: Harper Row. 1979.
- STROEBE, M. Coping with bereavement; a review of the grief hypothesis. *Omega, Journal of Death and Dying*, 1992/3, 26, pp.19-42.

STROEBE, M. From mourning and melancholia to bereavement and biography: an assessment of walter's new model of grief. *Mortality*, 1997, 2, pp. 255-62.

STROEBE, M. New directions in bereavement research: exploration of gender differences. *Palliative Medicine*, 1998, 12, pp.5-12.

STROEBE, M., GERGEN, K., GERGEN, M. & STROEBE, W. Broken hearts or broken bonds: love and death in historical perspective. *American Psychologist*, 1992, 47, pp 1205-1212.

STROEBE, M., STROEBE, W. & HANSSON, R. *Handbook of bereavement theory, research & intervention*. Cambridge: Cambridge University Press. 1993.

STROEBE, M. & SCHUT, H. A model for coping with grief and it's practical applications for the bereavement counsellor. In PAYNE, S., HORNE, S. & RELF, M. *Loss and bereavement*. Buckingham: Open University Press. 1999.

STROEBE, M and SCHUT, H. Culture and grief. *Bereavement Care*, 1998, 17, pp. 7-10.

STORR, A. *Solitude*. London: Harper Collins. 1997.

SULLENDER, R. Three theoretical approaches to grief. *The Journal of Pastoral care*, 1979, Dec, p.248.

SYMES, T. What comfort for this grief. *Professional Nursing*, 1991, 6, pp.437-441.

TALBOT, K. Mothers now childless: structures of the life-world. *Omega*. 1997, 36, pp.45-62.

TATLEBAUM, J. *The courage to grieve: creative living, recovery & growth* New York: Lippincot & Crowell. 1980.

TEDESCHI, R. & CALHOUN, L. *Traumatic and transformation: growing in the aftermath of suffering*. London: Sage. 1995.

THEARLE, M. Church attendance: religious affiliation and parental responses to sudden infant death. *Omega, Journal of Death and Dying*, 1995,31, pp.51-58.

THOMAS, V., STRIEGEL, P., DUDLEY, D., WILKINS, J. & GIBSON, D. Parental grief of a perinatal loss: a comparison of individual and relationship variables. *Journal of Personal and Interpersonal Loss*, 1997, 2, pp.167-187.

THORNHILL, R. & THORNHILL, N. The evolution of psychological pain. In BELL, R. & BELL, N. *Sociobiology and the Social Sciences*. Lubbock, Texas: Texas Technical University Press, 1989, pp.73-103..

TINSLEY, E. Surgeons, nurses and bereaved families attitudes. *Burns*, 1994, 20, pp.79-82.

TURNER, R. *Family interaction*. New York: John Wiley. 1970.

TUTTY, L. Theoretical and practical issues in selecting a measure of family functioning. *Research on Social Work Practice*, 1995, 5, pp.80-106.

TRIANDIS, H.C. & LAMBERT, W. W. (ed.). *Handbook of cross-cultural psychology*. Boston: Allyn & Bacon. 1980.

TROLLEY, B. Kaleidoscope of aid for parents whose child died by suicidal & sudden, non suicidal means. *Omega, Journal of Death & Dying*, 1993, 27, pp.239-250.

TWOMEY, J. Loss and replacement: intergenerational dynamics related to a two year old. *Infant Mental Journal*. 1995, 16, pp.144-154.

VALERIOTE, S. & FINE, M. Bereavement following the death of a child *Contemporary Family Therapy*, 1987, vol.9, 3, pp. 202-217.

VERNON, G. *Sociology of death: an analysis of death related behaviour*. New York: Ronald Press.1970.

VIDEKA-SHERMAN, L. The effects of participation in a self-help group for bereaved parents. *Prevention In the Human Services*, 1982, spring, pp. 69-77.

VIDEKA-SHERMAN, L & LIEBERMAN, M. The effects of self help and psychotherapy intervention on child loss: the limits of recovery. *American Journal of Orthopsychiatry*, 1985, 55, pp.70-82.

VIDEKA-SHERMAN, L. Research on the effect of parental bereavement: implications for social work intervention. *Social Services*, 1987, Vol.61, pp.102-116.

WALKER, T. *On bereavement - the culture of grief*. Buckingham: Open University Press. 1999.

- WALLERSTEDT, C. & HIGGINS, P. Facilitating perinatal grieving between the mother and the father. *Journal of Obstetrics and Gynecology and Neonatal Nursing*, 1993, 25, pp.325-334.
- WALSH, F. & Mc.GOLDRICK, M. *Living beyond loss, death in the family*. New York: Norton.1991.
- WALTER, T. A new model of grief: bereavement and biography. *Mortality*, 1996. 1, pp.7-27.
- WEIS, R. S. The provisions of social relationships In RUBIN, Z. (ed.). *Doing unto others*. Englewood Cliffs: Prentice -Hall. 1974.
- WEISS, R. The emotional impact of marital separation. *Journal of Social Issues*, 1976, 32, pp.135-145.
- WEISS, R. Loss and recovery. In STROEBE, W & HANSSON, R. (eds.). *Handbook of bereavement*. Cambridge: University Press.
- WEISS, R. *Going it alone*. New York: Basic Books. 1979.
- WEISS, R. Attachment in adult life. In PARKES, C. M. & STEVENSON - HINDE (eds.). *The place of attachment in Human Behaviour*. New York: Basic Books.1982
- WEISS, R. The attachment bond in childhood and adulthood. In PARKES, C. M., STEVENSON-HINDE, J. & MARRIS, P. *Attachment across the life cycle*. London: Routledge.1991.
- WEINSTEIN, N. D. Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, 1980, 39, pp.806-820.
- WEIS, R. Loss and recovery. *Journal of social Issue*, 1988, 44, pp.37-52.
- WELLENKAMP, J. C. Notions of grief and catharsis among the Toraja. *American Ethnologist*, 1988, 15, pp.486-500.
- WIENER, L., AIKIN, A., GIBBONS, M. & HIRSCHFELD, S. Visions of those who left too soon. *American Journal of Nursing*, 1996, 96, pp.57-61.
- WILLIAMS, R. Reflections on the impact of loss of an adult child in the grief experiences of bereaved parents.In MARGOLIS, O. et al. *Grief and the loss of an adult child*. New York:Praeger. 1988.

WILSON, A. LAWRENCE, J. STEVENS, D. & SOULE, D. The death of the newborn twin an analysis of parental bereavement. *Pediatrics*, 1982, 70 pp. 587-591.

WOODWARD, K. Motherhood: identities, meanings and myths. In WOODWARD, K. (ed.). *Identity and Difference*. London: Sage. 1997.

WORDEN, J. *Grief counselling and grief therapy: a handbook for the mental health practitioners*. New York: Springer. 1982.

WORTH, N. Becoming a father to a stillborn child. *Clinical Nursing Research*, 1997, 6, pp.71-89.

WORTMAN, C. & SILVER, R. The myth of coping with loss. *Journal of Consulting and Clinical Psychology*, 1989, 57, pp. 349-357.

WRIGHT, J., ALDREDGE, J., GILLANCE, H. & TUCKER, A. Hospice-based groups for bereaved siblings. *European Journal of Palliative Care*, 1996, 3, pp.10-15.

ZALL, D. Long term affects of childhood bereavement - impact on roles as a mother. *Omega, Journal of Death & Dying*, 1994, 29, pp.219-230.

ZISOOK, S. Bereavement and unresolved grief in psychiatric out patients. *Omega, Journal of Death and Dying*, 1989, 20, pp.307-322.

APPENDICES

1 THE BEREAVEMENT WEB

A guide to help our understanding of the grief experience is to imagine that the bereaved parent has become entangled within a complicated spider's web. This web will be unique to each individual in their loss. Factors such as a person's physical and emotional well-being will alter how they react in bereavement. The social support around the bereaved will also alter their long term outcome. Other factors will include a person's psychological and spiritual outlook on life (Figure 8). Each individual strand of the web has a direct affect upon other strands. As the bereaved parent moves forward there seems always to be some presence of this web clinging to them (Figure 9).

FIGURE 8

THE BEREAVEMENT WEB

HOLISTIC PERSPECTIVE OF THE BEREAVED

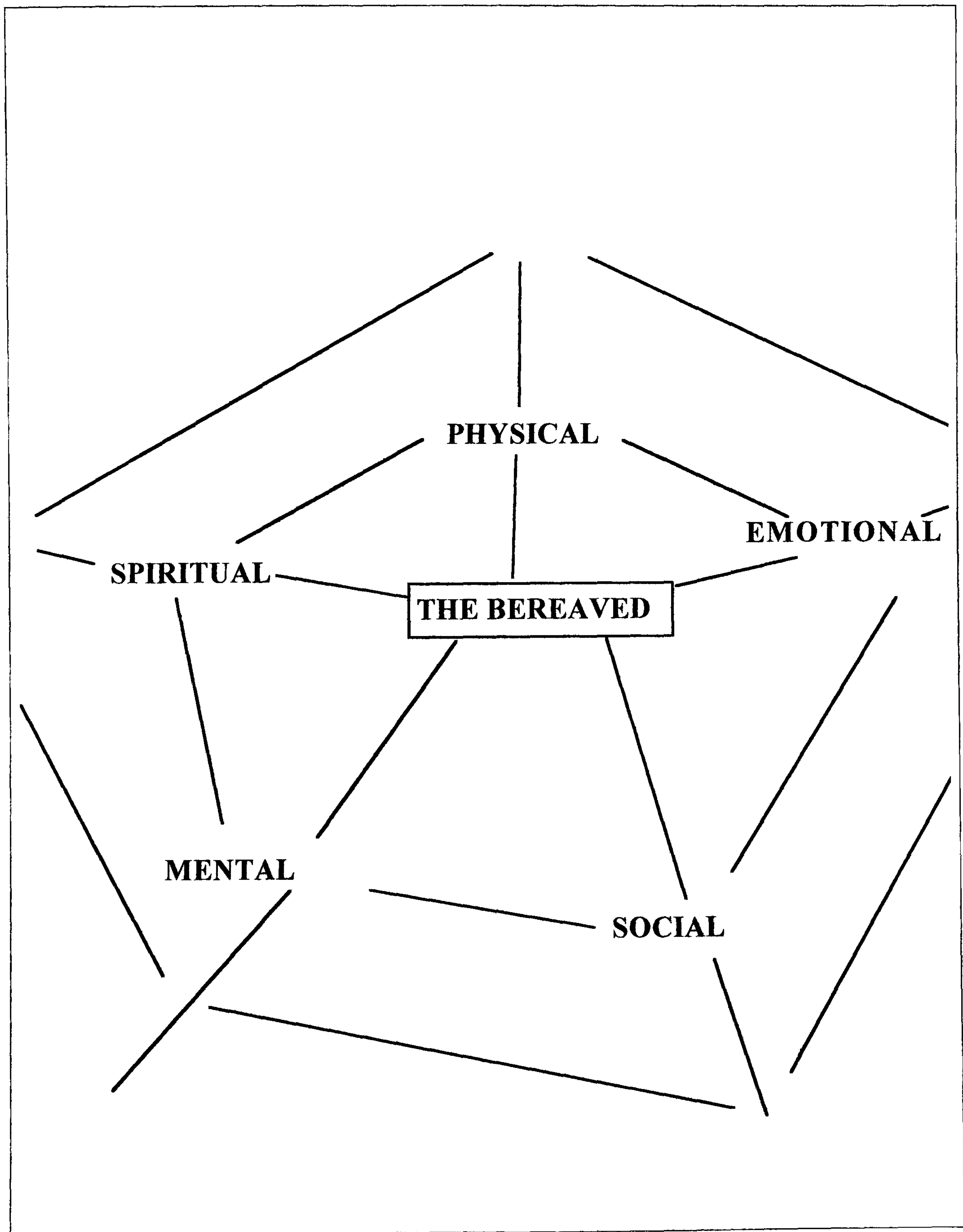
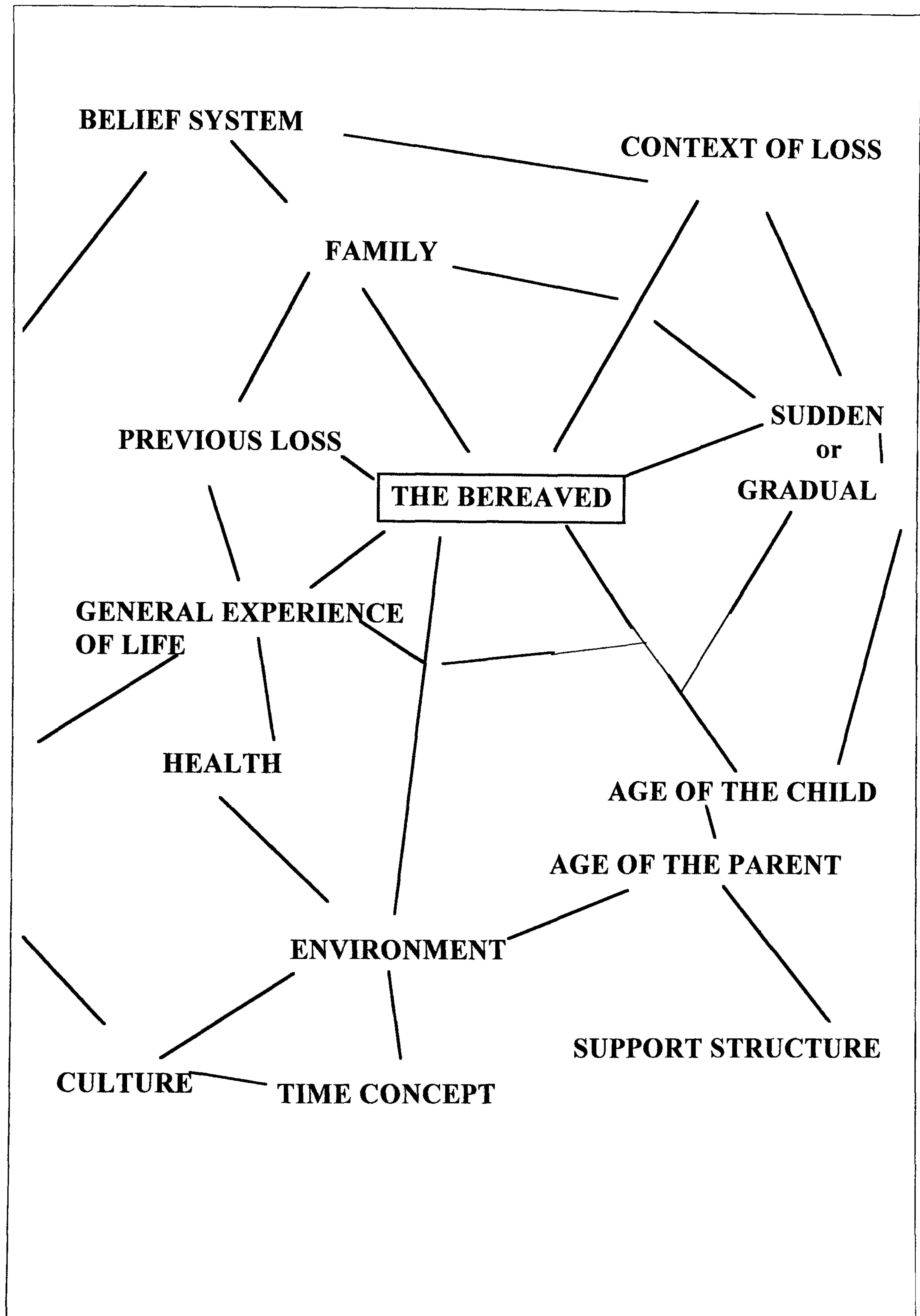


FIGURE 9 THE COMPLEXITY OF THE BEREAVEMENT WEB
 MULTIPLE FACTORS AFFECTING THE BEREAVED



It is understandable that grief from this picture manifests itself in numerous facets (Feifel,1998). These differing components affecting the bereaved can be seen from the variety of research carried out specifically in regards to the loss of children. Appendices 2 to 4 consider some of these factors.

2. GENDER DIFFERENCES

Gender differences have been identified in the bereavement process. Peppers and Knapp (1980) found mother's loss more intense than father's and suggested it was due to the strong affectional bond in pregnancy along with the mothering role as a socialiser and nurse with the child. They felt secondly that there was a cultural expectation where men were victims of the "masculine must be strong" ethic. One must question whether this is really the case for fathers. Certainly the marital relationship is particularly vulnerable after a child dies. Videka-Sherman & Lieberman (1987) found high levels of stress in married couples but found no evidence that the divorce rate of bereaved parents approached the 80% level, a figure reported by Schiff (1977). However both studies are from America, and so there is a need to clarify whether women do suffer more than men in Britain.

Cooke (1983) did find evidence of "Discrepant Coping", where one parent expresses their feelings negatively (anger, grief, guilt), while the other partner did not. This led to poor communication and one partner being perceived as weak. Cooke found that men in particular expressed themselves as if "something was missing". They had a tendency to deal with the difficulties more personally and felt responsible for managing and controlling the family grief. Opposite to prediction, husband's did not turn to religion more than wives, but felt more a loss of direction and purpose in life. Sherman (1982) studied 64 spouse pairs after their children died from a variety of causes. He found husbands and wives coped differently with grief. Women reported

using more coping strategies of all types. Women also reported poorer marriage quality than did their husbands. Even families with previous strong and stable relationships described strain caused by the loss and individual grief reactions. Fathers sometimes took refuge in their work and preferred not to dwell on the loss, while mothers wanted to talk about the child and to express their pain through crying. An unexpressive grieving style results in emotional unavailability to the expressive spouse and therefore add to the burden of expressive grief (Pearn, 1977).

3 THE EARLY STAGE OF THE LOSS OF A CHILD

Anticipatory grief plays its normal role of assisting in the process unless it proves to be excessively long in time. In the early stages of bereavement, family and community are particularly supportive to the family. The number attending funerals for children is usually high, which parents describe as being comforting at the time.

In the early months one might not recognise any significant difference in the grief as compared to perhaps the loss of a partner. Yet there are signs of the uniqueness of this kind of loss. The ongoing tears, sensing the presence of the deceased, dreams, holding onto possessions would be expected. However the social isolation and sense of avoidance by the community begins to show that the loss is of a unique kind of experience. The splitting of parents from the community is intensified by the rift that forms within families themselves as they grieve in their own individual way.

In the first year one might simply say that the grief is intense but not particularly abnormal compared to other losses. As the second and third year approaches one can begin to see the depth of grief endured. The hope that the pain of grief will decrease is now lost as parents discover that the heartache endures as intensively as in the first year. Parents are often by now more socially isolated. Often the deceased's clothes and bedrooms are still untouched. The parent feels distant from the events of the past which only heightens their despair. There is a lack of desire to want to move on. If other siblings are present then tension can arise within the family as the parents

become either over protective of the child or develop a tendency to give them everything they ask for, for fear of upsetting them. When parents are young enough to have other children it has been found that the parent can idealise the deceased thus giving extra problems for the new child who cannot live up to an unreal expectation.

4 THE EFFECTS OF CHILD LOSS UPON MARRIAGES

There is evidence that highlights the strain placed upon marital relationships. A husband and wife relationship is often strained during the months of following along beside a terminally ill child (Knapp, 1986). Mothers have primary responsibility for the care of the child during a long drawn out terminal illness. The father may be around but not usually continuously. Therefore the mother and father often proceed through the illness and experience the emotional ravages of the encounter at different rates and with differing degrees of intensity. This can result in the collapse of effective communication channels between family members. Inability to draw support from a spouse when one needs it can lead to a feeling of resentment and even hostility, which in turn can permanently affect the relationship in a way that may be detrimental to the marriage.

Staudacher (1987) outlined five possible areas of conflict for a grieving couple:

- 1) Partners are undergoing the stress produced from grief and its accompanying conditions;
- 2) Partners become mediators as conflicts arise among siblings;
- 3) One or both spouses may be coping with job pressures which have magnified because of absence from work;
- 4) One or both spouses may find that responsibilities which once seemed routine now seem monumental;

- 5) Parents often have a heavy financial burden resulting from their child's illness or accident.

Staudacher estimates that 90% of all couples who lose a child are confronted by some serious marital problem within the first year after the child's death. Further, the divorce rate is exceptionally high among couples who have lost an only child. In many cases, the marriage which ends in divorce appears not to have been one which worked well before the death. The tragedy puts damaging strains on an already exacerbated relationship (Staudacher, 1987).

Unlike Videka-Sherman & Lieberman analysis of not seeing a high divorce rate after the loss of a child, Knapp (1986), quoting the Minneapolis Tribune of October 17 1982, suggests that statistics show that in approximately 70% of the families of children killed violently, the parents end up in the divorce courts or become separated. Minor problems, that were perhaps more of a pest than anything else before the murder, become blown into exaggerated major concerns after the murder. Further, parents are often maligned by their parents, neighbours and friends, who find them somehow at fault.

The old cliché a "grief shared is a grief halved" does not seem to apply here. There seems to be little sharing, support, comforting, communication, between two people who are themselves coming apart at the seams. It is difficult to support another person when you yourself are struggling desperately just to keep afloat. So parents lose their confidence in their ability to keep the family functioning. Parents lose their

spontaneity, homemaking activities come to a standstill. Where strong family ties and good communication patterns existed prior to the loss, where families are close knit and mutually supportive, they are more likely to survive the loss with fewer negative effects. This is an important point if we are to support families better in the future. However there is a need to find out how marriages that stay together are coping also. Donnelly (1982) backs this up when she investigated the reasons for a high rate of separation and divorce.

She questioned whether the marriages that end may have been vulnerable regardless of the loss, functioning more as parents than partners. They may have done a lot of blaming the other rather than take responsibility for their own part in a problem.

There is no doubt that tensions arise within family life with the death of a child. However one needs to be careful not to generalise from small sample bases. Riches has helpfully observed how fathers particularly put their energies into managing practical issues, supporting their partners and controlling their own emotions. This is a form of 'rationalising the loss,' in terms of the wider needs of the family (Riches & Dawson, 2000). Littlewood (1992) suggests that this pattern for men may not be a good coping strategy for them in the long run as they eventually lose their strategy for coping with the grief. What is clear is that supporters, counsellors and health visitors need to recognise that partners often function in different cultural ways which means that the bereaved need to be supported in a way that is appropriate for them.

5. THE BONDING PROCESS

The attachment of a child to the parent influences the child's future relationships with his/her own child. Main et al (1985) carried out extensive investigations asking parents about their attachment relations in childhood, and the influence of these early relations on their own development. This revealed three patterns of responding.

Autonomous-secure individuals were able to give a clear and coherent account of early attachments. Preoccupied individuals produced many conflicting childhood memories about attachment, but could not draw these together into an organised, consistent picture. Finally, dismissing individuals often claimed that they could not remember much about relations with parents in childhood. They tended to idealise their parents on a general level, but to disclaim any influence of attachment experiences on their own development, or to report memories of rejection when they did manage to remember specific episodes (Parkes, 1991).

Such memories are associated with parental identification with the child such that the child becomes 'a reproduction of the parent.' Here the parent may relive her or his life which may involve some ambivalence both within the parent and between the parent and the child. Benedek suggests that one of the tasks of the parent is to counter identification with the child so as to separate the child from the self. Such identification is associated with empathy and the consideration of the child in his or her own terms.

6. THE CONTINUOUS BOND

Dennis Klass (1996) takes this view further by suggesting the concept of a continuing bond between the bereaved and the deceased. Klass along with Silverman and Nickman found parallel links with their research in dealing with families in significant loss.

Initially, we became aware that both bereaved children and bereaved adults were struggling to find a way of maintaining a connection to the deceased. We were surprised when we found parallels in the experience of adoptees who had a relationship with a 'fantasy' birth parent, even when they were adopted at birth. We found that older adoptee's who had known their birth families were also maintaining a continuing internal connection with them. Research interviews with children whose parents had died revealed that in the first years after the death, they developed a set of memories, feelings, and actions that kept them connected to their deceased parent. Rather than letting go, they seemed to be continuing the relationship. We observed that they kept this relationship by dreaming, by talking to the parent, by believing that the parent was watching them, by keeping things that belonged to the parent, by visiting the grave, and by frequently thinking about the dead person. It was also clear that these connections were not static, but developed over time so that the child-parent relationship was developmentally appropriate to the child and to the child's present circumstances' (Klass, Silvermann, and Nickman, 1996).

Klass et al also found college age women whose parents died when they were young reporting a desire to know more about the deceased parents from the perspective of a young adult, to connect with the deceased in a different way.

Klass and his colleagues concluded that survivors hold the deceased in loving memory for long periods, often forever, and that maintaining an inner representation of the deceased is normal rather than abnormal. Here the relationship with the deceased is seen as interactive, even though the other person is physically absent. The survivor's experience can be described in terms of interfaces with the survivor's inner representation of the deceased, and with the living community that surround's the survivor. Each of these influence the other. The relationship with the inner representation influences how survivors behave in the community of the living people. The living, whether they are immediate family, cultural group, or larger society, can influence the individual's desire and ability to remain involved with the deceased. However in describing this, Klass acknowledges that there is no clear understanding of the inner representation of the dead person.

Normand (1994) described this representation as a living legacy. Other authors have described the activities that keep this memory alive. Hogan and De Santis (1996) described the continuous connection in terms of an ongoing conversation that the bereaved has with the deceased: expressing their regret about what happened, asking why it happened, bringing them up to date and asking for their help. As we try and understand the nature of the long term affect of the loss of children in particular, we

need to ask what kind of bond exists between parent and child? How does the relationship prior death help us in our understanding? Can we talk about this bond in Bowlby's (1980) sense of attachment with its internal working model which gives an evolving representation rather than a memory?

Is this long term affect characteristic purely in the west with it's strong association with smaller families and a society that is at present particularly child focused?

What is clear so far is that as parents move on with their lives, they carry with them a daily affect of their loss. This is not something that they try and shake off, but rather see it as simply a sign of who they have become.

7. THE GRIEF EXPERIENCE INVENTORY

Immediately after the death I felt exhausted.
 I tend to be more irritable with others.
 I am strongly preoccupied with the image of the deceased.
 I frequently experience angry feelings.
 It is not difficult to maintain social relationships with friends.
 My arms and legs feel very heavy.
 I am unusually aware of things related to death.
 It seems to me that more could have been done for the deceased.
 I showed little emotion at the funeral.
 I felt a strong necessity for maintaining the morale of others after the death.

I feel cut-off and isolated.
 I rarely take aspirins.
 I feel reluctant to attend social gatherings.
 I was unable to cry at the announcement of the death.
 I have feelings of guilt because I was spared and the deceased was taken.
 I have a special need to be near others.
 I often experience confusion.
 I feel lost and helpless.
 I am comforted by believing that the deceased is in heaven.
 I have had frequent headaches since the death.

It is as difficult to part with the clothing and personal effects of the deceased.
 It is as necessary to take sleeping pills after the death.
 My yearning for the deceased is so intense that I sometimes feel physical pain in my chest.
 I cry easily.
 I have taken tranquilizers since the death.
 I experience a dryness of the mouth and throat.
 I am restless.
 On first learning of the death I had a dazed feeling.
 Concentrating upon things is difficult.
 I have feelings of apathy.

31. I experienced a feeling when the death occurred that "something died within me"
32. Aches and pains seldom bother me
33. I find I am often irritated with others.
34. I could not cry until after the funeral.
35. I feel that I may in some way have contributed to the death.
36. I find myself performing certain acts which are similar to ones performed by the deceased.
37. I made the funeral arrangements.
38. I lack the energy to enjoy physical exercise.
39. I rarely feel enthusiastic about anything.
40. I feel that grief has aged me
41. I have never dreamed of the deceased as still being alive.
42. I find myself frequently asking "why did the death have to happen in this way?"
43. I sometimes have difficulty believing the death has actually occurred.
44. I feel a strong desire to complete certain unfinished tasks the deceased had begun.
45. I have often dreamed of times when the deceased was living.
46. I am often irritable.
47. I have dreamed of the deceased as being dead.
48. I feel extremely anxious and unsettled.
49. I feel tenseness in my neck and shoulders.
50. Sometimes I have a strong desire to scream.
51. I am so busy that I hardly have time to mourn.
52. I feel anger toward God.
53. I have the urge to curl up in a small ball when I have attacks of crying.
54. I feel the need to be alone a great deal.
55. I rarely think of my own death.
56. I find it difficult to cry.
57. Looking at photographs of the deceased is too painful.
58. Life has lost its meaning for me.
59. I have no difficulty with digestion.
60. I have had brief moments when I actually felt anger at having been left.

have no trouble sleeping since the death.
 have a hearty appetite.
 feel healthy.
 it comforts me to talk with others who have had a similar loss.
 I yearn for the deceased.
 I seldom feel depressed.
 I have the feeling that I am watching myself go through the motions of living.
 Life seems empty and barren.
 There are times when I have the feeling that the deceased is present.
 I often take sedatives.

I have frequent mood changes.
 The actions of some people make me resentful.
 My feelings are not easily hurt.
 I am losing weight.
 Small problems seem overwhelming.
 I sometimes feel guilty at being able to enjoy myself.
 I frequently have diarrhea.
 I often wish I could have been the one to die instead.
 I have lost my appetite.
 I sometimes talk with the picture of the deceased.

I am not interested in sexual activities.
 At times I wish I were dead.
 It is hard to maintain my religious faith in light of all the pain and suffering caused by the death.
 I seem to have lost my energy.
 I dread viewing a body at the funeral home.
 I find myself idealizing the deceased.
 I have problems with constipation.
 I frequently take long walks by myself.
 I avoid meeting old friends.
 I have a special need for someone to talk to.

I often feel as if I have a lump in my throat.
 I sometimes find myself unconsciously looking for the deceased in a crowd.
 I seem to have lost my self-confidence.
 I drink more alcohol now than before the death.
 After the announcement of the death I thought, "This could not be happening to me."
 I have nightmares.
 The thought of death seldom enters my mind.
 I have never worried about having a painful disease.
 Funerals sometimes upset me.
 I could not feel uneasy visiting someone who is dying.

101. I often worry over the way time flies by so rapidly.
102. I have no fear of failure.
103. I am close with only a few persons.
104. The sight of a dead person is horrifying to me.
105. I always know what to say to a grieving person.
106. I often seek advice from others.
107. It does not bother me when people talk about death.
108. I cannot remember a time when my parents were angry with me.
109. I do not think people in today's society know how to react to a person who is grieving.
110. I never have an emotional reaction at funerals.
111. I often think about how short life is.
112. I am not afraid of dying from cancer.
113. I do not mind going to the doctor for check-ups.
114. I shudder at the thought of nuclear war.
115. The idea of dying holds no fears for me.
116. I never lose my temper.
117. I have always been completely sure I would be successful when I tried something for the first time.
118. I am not usually happy.
119. I feel that the future holds little for me to fear.
120. I cannot ever remember feeling ill at ease in a social situation.
121. I find myself sighing more now than before the death.
122. I spent a great deal of time with the deceased before the death.
123. I find that comforting others helps me.
124. My family seems close to me.
125. I feel that I did all that could have been done for the deceased.
126. My religious faith is a source of inner strength and comfort.
127. I am smoking more these days.
128. I am not a realistic person.
129. I am awake most of the night.
130. I feel exhausted when I go to bed but lie awake for several hours.
131. I lose sleep over worry.
132. I often wake in the middle of the night and cannot get back to sleep.
133. I sleep well most nights.
134. Things seem blackest when I am awake in the middle of the night.
135. I can sleep during the day but not at night.

8. THE PARENTAL INTER-RELATIONSHIP QUESTIONNAIRE

PLEASE IGNORE
THE NUMBERS

Name: _____ (M / F)	1	2		(7)
Today's date: _____	1	2		(8)
Name of deceased: _____ (M / F)	1	2		(9)
Age at death: 0-2 2-10, 11-18, 18+	1	2	3	4 (10)
Type of death: illness, suicide, accident, other	1	2	3	3 (11)
Time of death: sudden within 24 hrs, 1-7 days 7 days+	1	2	3	4 (12)
Time since death: 0-2 yrs 3-5 yrs 6-10 yrs 10 yrs+	1	2	3	4 (13)
Number in family now : Adults: 1 2 3 4	1	2	3	4 (14)
Number in family now : Children: 1 2 3 4	1	2	3	4 (15)
Occupation: Professional Manual Housewife Other	1	2	3	4 (16)
Education: School: College/University:	1	2		(17)
Accommodation: Det: Semi: Terr: Flat:	1	2	3	4 (18)
Medical History: Yourself: Well _____ Illness: _____	1	2		(19)
Partner: Well _____ Illness: _____	1	2		
Children: Well _____ Illness: _____	1	2		
Any previous bereavements before the loss of child: Yes No	1	2		(20)
When asked "How many children do you have?", do you include the deceased?:				
Yes: No: Indirectly yes:	1	2	3	(21)
Do you regularly visit the doctor:				
Before loss: 1st yr: now:	1	2	3	(22)
Do you take prescribed drugs:				
Before loss: 1st yr: present:	1	2	3	(23)
Have you ever had symptoms similar to the deceased? Yes No	1	2		(24)
a. Do you use alcohol: Yes/No	1	2		(25)
b. If Yes: Has your consumption increased/decreased since loss:	1	2	3	

Do you feel you have experienced a breakdown?

Yes: No: Almost: 1 2 3 (26)

Has your involvement in the community:

increased: decreased: same: 1 2 3 (27)

Has your number of friends in the neighbourhood:

increased: decreased: same: 1 2 3 (28)

Have you links with support groups: Yes: No: 1 2 (29)
State:

Have you raised finance for charities since loss: Yes: No: 1 2 (30)

Do you support others in similar situations: Yes: No: 1 2 (31)

Has your relationship at work:

improved: same: deteriorated: 1 2 3 (32)

Was your employer supportive: Yes: No: 1 2 (33)

Are you interested in promotion:

a. Before: Yes: No: 1 2 (34)

b After: Yes: No: 1 2

Do you attempt to avoid people:

Work: Yes/No Neighbourhood: Yes/No 1 2 3 4 (35)

Do people attempt to avoid you: Yes: No: 1 2 (36)

Do you believe in God: Before: Yes/No After: Yes/No 1 2 3 4 (37)

Has your belief in God: same/changed increased/decreased 1 2 3 4 (38)

Do you have contact with a church:

a. Before: Yes: No: After: Yes: No: 1 2 3 4 (39)

b. Has your contact with Church: increased: decreased: same: 1 2 3

Have you experienced a funeral: Before loss: Since loss: 1 2 (40)

Have you avoided a funeral since: Yes: No: 1 2 (41)

Did you believe in the afterlife: Before: Yes/No Now: Yes/No 1 2 3 4 (42)

Was the funeral a comfort to you: Yes/No 1 2 (43)

Any particular part:

Music: Talk: No. of People: Prayers: 1 2 3 4 (44)

Did the deceased play any particular role in the family, please circle:

center of attention	bringing contact with others	focus of joy	1	2	3	(45)
center	friend	focus of discussion	4	5	6	
decision maker	pain bearer	focus of arguments	7	8	9	
	joker	other? - state:	V	X		

Has anyone else filled one of these roles since loss, state:

Husband/Wife	Son/Daughter	Friend	1	2	3	(46)
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What has been the hardest time since loss:

Xmas	Holiday	Anniversary	Other	1	2	3	4	(47)
Birthday				5				

Has anything/person helped to fill the gap left:

Husband/Wife	Son/Daughter	Friend	Work	1	2	3	4	(48)
--------------	--------------	--------	------	---	---	---	---	------

Have fringe relatives been:	more helpful:	less helpful:	1	2		(49)
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Have friends been:	more helpful:	less helpful:	1	2		(50)
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Has the marriage relationship:

improved:	same:	deteriorated:	1	2	3	(51)
-----------	-------	---------------	---	---	---	------

Has ones sexual activity:

improved:	same:	deteriorated:	1	2	3	(52)
-----------	-------	---------------	---	---	---	------

Do you spend time together:	same:	more:	less:	1	2	3	(53)
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If you argue is there a main theme:

Marriage:	Children:	Past:	1	2	3	(54)
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Future:	Other:	4	5			
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Has your control of children:	increased:	decreased:	1	2		(55)
-------------------------------	------------	------------	---	---	--	------

Before: 1st Year: Now:

Have you felt:						
excessive anger	1	2	3			(56)

jealous	1	2	3			(57)
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fear of further loss	1	2	3			(58)
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wished to die	1	2	3			(59)
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agitated	1	2	3			(60)
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lost concentration	1	2	3	(61)
character - more like deceased	1	2	3	(62)
sense of presence of the deceased	1	2	3	(63)
Have you felt angry towards the deceased: Yes/No	1	2		(64)
If Yes - does this make you feel guilty: Yes/No	1	2		(65)
Have you a special object/room: Room: Photo: Other:	1	2	3	(66)
Do you feel you have come through bereavement: Yes: No:	1	2		(67)
Do you still feel you have problems to resolve: Yes: No:	1	2		(68)
What emotions have come to the surface in filling in this questionnaire?				
anger Guilt Tears	1	2	3	(69)
Loss Lonely Pain/sadness	4	5	6	
none	7			

9. SUMMARY OF SUB-SCALES

Despair

The despair scale measures the mood state of the respondent, characterised generally by pessimism of outlook on life, feelings of hopelessness or worthlessness, slowing of thoughts or actions, and low self-esteem. The despair scale is the longest and most reliable of the bereavement scales.

Anger/Hostility

The anger/ hostility scale indicates an individual's level of irritation, anger, and feelings of injustice. individuals who score high on this scale are restless, agitated and angry. They are likely to be touchy, irritable and to lose their tempers over small matters.

Guilt

The guilt scale is an expression of feeling somehow responsible for the death or in some way to blame. Items also tap feelings that come about for having survived the deceased.

Social Isolation

The social isolation scale samples behaviours characterised by withdrawal from social contacts and responsibilities. Such people withdraw not only by their own choosing but by their feelings of isolation by others.

Loss of Control

The loss of control scale indicates a person's inability to control his overt emotional experiences. Many of the items deal with crying.

Rumination

The rumination scale measures the amount of time spent with thoughts concerning the deceased or preoccupation with thoughts of the deceased. There can also be a degree of brooding - a combination of rumination and anger, a looking for someone to blame.

Depersonalisation

This scale measures the numbness, shock, and confusion of grief. This is particularly evident when a death is unexpected or when severe feelings of loss of control of one's environment or universe ensure.

Somatisation

This scale measures the extent of somatic problems which occur under the stress experience.

Death Anxiety

This scale measures the intensity of one's personal death awareness.

10. PRELIMINARY INVESTIGATION INTO BEREAVEMENT IN A NON-WESTERN CULTURE

The general picture of adult grief has been well researched (Parkes,1972). Early documentation of manifestations of adults' responses to another persons death, and to anticipation of their death, provided a classical model of grief that includes shock and denial, anger, depression, acceptance, and restitution (Kubler-Ross,1983). Since that time, other descriptions of grief have evolved as the basis for interventions with the bereaved (Worden,1982).

The author's own research found evidence of prolonged grief in parents who had been bereaved of a child over ten and fifteen years (Merrington,1995). Merrington following Knapp (1986) attributed this to the concept of Shadow Grief. Klass (1996) supports this general view in expounding the concept of 'continual bonds' which remain throughout the life of the bereaved parent.

Viewed from 'inside', mourning is as much the beginning of an imaginable relationship as it is to the ending of the material one (Mogenson,1992).

However almost all research has been on white middle class bereaved parents.

Although Bowlby (1981) argued that cross - cultural evidence is sufficient to show that emotional responses of the bereaved are very similar, we do not have any large inclusive studies by which to compare the parental grief experience.

A current need in bereavement research is to identify whether the concept of Shadow Grief can be identified cross-culturally. The common and unique stress factors associated with variable child bereavement have been investigated in the west (Merrington,1995). However there is little published evidence from parental bereavement research in non western, and particularly African cultures. An assessment of the characteristic and behavioural factors in shadow grief in non western cultures will enable an evaluation to be made of any universal core factors as compared to cultural and local manifestations of grief.

The loss of a child through death has been described as having unique features (Knapp,1986). From five years experience in the role of a Hospital Chaplain of a Maternity Hospital, I have observed the initial impact of the death of prenatal and full term babies upon their parents. This has involved observing and supporting a minimum of fifty sets of bereaved parents. Even when parents have had an opportunity to prepare for the death, the grief experienced is both intense and long lasting (Merrington,1995).

It is not uncommon to find parents with unresolved issues because of the death years later. I found that when asking parents whether they had come through their grief they would answer yes. However if you asked them whether they still had issues to resolve linked to their loss they would reply in the affirmative (Merrington,1995).

It was clear from my experience that parents were experiencing difficulties over a long period of time. It is clear from the diagram on page 72 that parents continue to exhibit difficulties arising from the death of their child years later. The percentage of parents who are still experiencing bereavement ten years afterwards is strong evidence for the existence of Shadow Grief. Further research is required to identify why parents see themselves having come through bereavement, yet acknowledging that they still have emotional baggage to deal with in relation to the loss. Although each bereaved parent's story is a unique experience, nevertheless there does appear to be a characteristic pattern to the bereavement process. Could this be simply a western approach to grief and bereavement?

In the West, the view of recovering from bereavement and 'putting it behind you' to build a new life has been well reported. Many parents are confused when this so-called process does not turn out as expected (Merrington, 1995). One suspects that each society formulates its own belief system about bereavement which encourages people to conform and react in a particular way. However if this belief system does not meet with the actual encounter a bereaved parent experiences then there will remain a degree of tension within the parent in relation to his or her society.

There is also the question of whether the grief of a parent differs in a country where the death of a child is less common as compared to a country where the death rate of children is particularly high. As a means of seeing whether Shadow Grief was just a

western phenomenon, and whether a different culture formulated appropriate patterns of grief behaviour, an investigation was carried out initially in Beirut, Lebanon and then more fully in Uganda and Tanzania.

Beirut was chosen as a locality because its inhabitants had experienced death over many years, mainly due to civil war. From 1943, when Lebanon declared itself independent, the country had found itself caught in a power struggle. More recently in 1973 there was fighting between the Palestine Liberation Organisation (PLO) and the Lebanese army, which led on to the fourth Arab - Israeli war. In 1975 fighting broke out in Beirut itself, fought largely between rival Lebanese militias. Lebanon was a young country with barely thirty years of independence when it erupted into a war that was at least as savage as the Spanish civil war forty years earlier (Gilmoor, 1983). Since the outbreak of the civil war in the mid 1970s, the city of Beirut has for many Lebanese been a divided city. It is now common to meet Christians who have not ventured from the east into the west Beirut since 1975, and Muslims who have not ventured to the east since the same time (Crooks, 1990). Relative peace had returned to the city by the beginning of the 1990s. From contacts with the Christian Missionary Society Chaplain in Beirut, it seemed that in this period of rebuilding of the city physically, people were beginning to bring order to their lives. However the reality of grief and bereavement was beginning to be expressed. It was thought that a visit to simply listen to peoples stories of grief would begin to

clarify whether shadow grief was present and whether a more detailed analysis would be necessary.

Locality & Context

In April 1996 few places in Lebanon could capture more poignantly the tragedy that is Lebanon than the city of Beirut. Despite extensive rebuilding taking place, the city was still in ruins with parts of the city still abandoned on what was called the green line where the civil war started. Contact had been made with a local refugee camp 2 kilometres outside Beirut.

Unfortunately the day before the interviewing was due to take place, Israeli forces bombed both the camp and parts of the city. Despite the problems, some interviewing did take place with bereaved parents who lived in the centre of the city itself.

7 parents were individually asked to share their story of their loss. Each interview took approximately one to one and a half hours with the aid of an interpreter in some cases.

GEORGE

George was a retired Lebanese Bank Manager in his early sixties. He was married with three children, living on the edge of a reasonably affluent part of Mansourette, of Ras Beirut.

On the final day of the civil war in 1991 his eldest son was killed. He was 35 years old.

As the war was coming to a close, there was one Christian group holding out refusing to surrender to the Syrians. George's family were in the basement waiting for the local bombardment to end. His son was living in the same neighbourhood with his wife and two daughters. They too were in the basement, however after two hours Raze went upstairs in the lull of fighting to get his medicine for his diabetes. In those few minutes a mortar bomb fell outside in the garden sending shrapnel through the window hitting Raze in the back. Raze's wife and daughters were getting worried and finally ten minutes later went up to find her husband seriously wounded. Alas, the Red Cross was not allowed to cross the lines because of the degree of bombing. It was 10 am in the morning. By 1 p.m. the Syrian troops had moved in and the war was over; perhaps Raze was the last casualty of the war. The family got him to hospital but he died one hour later. The custom in Lebanon is to have the funeral within twenty-four hours.

The family gathered together in George's home, he felt it was his duty to care for Raze's family. They opened their home for three days for relatives, friends and neighbours to give their respects. As a Christian of a Baptist Church, George didn't want his daughter-in-law to dress in black. However, if a widow doesn't, then people may feel that she didn't care for her husband. So Raze's wife dressed in black for a month and then gradually began to wear dark coloured clothes other than black.

George, in the loss of his son, found comfort in the fact that Raze had been deteriorating in terms of his diabetes. He felt that perhaps God had spared him from further suffering. George's Christian belief made him accept the fact that God knew best, he said he felt no anger at the people who fired the bomb. After one year George's daughter-in-law and family went back to her own home but was continued to be supported by the wider family. Raze's wife and mother still felt too upset to talk about their loss. George acknowledged that a day did not pass without him thinking about his son. The bombing which had started the day previously had also brought back many memories and fears for the family. The deceased sons family moved back into George's home on the day following the interview. I visited this home the day after they moved in and found a tense worried family intensely watching the television for news of further bombing.

ALICE

Alice was a lady in her fifties who worked daily at a local orphanage cleaning and doing household chores. She had three children, Joseph who would have been 36, Deena 34, and Antonio, 29 years old. They had been an affluent family with their own business, until the death of her husband. During the civil war when the Syrians had taken control, her eldest son disappeared. He had got married but Alice said it was not a good marriage because it was his wife who told the Syrians to come and take him from the house.

"She complained against him to the Syrians. His wife was not a good wife as believers we can say nothing but that. Because they cannot divorce she wanted to get rid of him so she complained to the Syrians against him"
(Interview).

Alice said she used to like her daughter in law. She gave her all her jewellery. But before Alice became an active Christian believer, she wanted to kill her daughter in law. She actually bought the weapon to do it.

In 1987, at the time of her boy being taken away, 16 other young men were taken but every one of these young men was to return to the town. And when they used to come back they used to tell her that they saw her son. Alice would go and try and find her son but each time she used to ask about him, the soldiers would tell her to come back in a month's time. Alice at this time was still full of hope. Some of the people from the prison came to her and said that they need about 100,000 Syrian lires in order to help him come out of prison. So she sold everything she had. She gave them the money but nothing happened. He husband went to the prison to get the boy or the money back but he was threatened to keep quiet or else the rest of the family would disappear. On his return home he had a stroke and died suddenly. Alice lost her business and her home. The Syrians took over her house, and Hezbollah occupied her house in the mountains. She lost all her clothes and furniture.

Alice said she still had a sense of humour but a terrible tragedy was in her heart. Since then, she now believes her son is dead. Her other son is at present in prison for a robbery she believes he did not do. Since becoming a Protestant her family who are Maronites have disowned her. No one really feels for her or knows what she is going through. Alice says that she thinks about Joseph daily.

" The Lebanese people smile and put on a show that everything is well but underneath they have lots of hurts and pains. One day you are happy and then when you remember your loss, you are sad once again" (Interview).

Alice still holds on to possessions that belonged to her son. She tells her grandchildren from the other son, that they belong to their uncle. Every year she still goes to Syria hoping that perhaps there could have been a mistake and he is still alive. The prison authorities tell her there is no such name in the camp. Her friends tell her that if he was alive she would have been able to see him. About two years after her son went missing Alice thought seriously about poisoning herself. It was at this time that she went back to Church.

JANETTE

Janette was an elderly women in her 70's. She lived in a fourth floor flat in a block of apartments on the edge of the green line. All around this area one could see only destruction from bombing. The building itself was aged through time and war.

The home of Jenette was a typical small apartment, with high rise buildings visible from every window, lookout point. She was an elderly frail lady who could have been anybody's grandma in one of many countries. Wearing her yellow cleaning apron she made us feel more than welcome as she fed us with special date cakes made especially for Easter. Her description of her life as a result of the bereavement of her two sons was identical to so many I'd heard before in Great Britain.

Jannette had three sons, two of which were killed by a bomb in 1985. They were twenty six and twenty four at the time of death. The boys both worked together driving an ambulance. Their job was to drive to areas where mortar bombs had exploded and to try and rescue anyone still alive. They would often return to her flat covered in blood from their job.

The eldest son was hurt by a bomb 2 years earlier but he recovered in hospital. However on another occasion the boys went to a bombed site just as another mortar was about to explode. They were both killed instantly. The mother went to see them. One son had his head almost blown off. She tried to repair the damage and held him in her arms.

Janette organised a typical Lebanese Funeral within twenty four hours of their death. The family would dress in black and hold open house for days for people to come and give their respects. Janette did not find this process easy to handle. Although she found it comforting when people came and gave their sympathy, she also found it extremely taxing and exhausting.

At first Janette visited her sons' tomb every day but now she only attends about twice a week. She finds it a relief to cry in front of them at the tomb. Her husband died when her sons were only eight, six and four years of age. She now finds herself clinging to her remaining son and grandchildren. Whenever the son has a headache or seems off-colour Janette worries that something might happen to him. She acknowledges that she accepts that her older sons are dead yet she goes to kiss them. In her small flat there are pictures of the two sons. Janette will often sit with her friends outside and talk about her children. The remaining son called his two children after his dead brothers.

" Even drinking coffee hurts because they loved to drink coffee together. It is a daily reminder of them" (Interview).

Janette does not feel any anger to those responsible for her children's death. She does not know even which side fired the bomb. When asked whether it helps that so many people had experienced bereavement she quoted an Arabic proverb which

says, ' the coal burns in its place and not elsewhere.' She feels with everybody, but her hurt is her own.

" The whole country is experiencing this together, yet everyone feels it individually" (Interview).

During the holidays, Christmas, Easter, and on her sons' birthdays, she would make cake and take it to their grave. She would find this a comfort . She would pull up a chair and talk to them about everything that had happened to her, she would also share her sadness with them. She feels with everybody who had experienced loss but her hurt is for herself.

Janette felt that her faith had not changed.

"The Virgin Mary also lost her son, but she only lost one as compared to my two. But God is helping her to support this tragedy. He must be because no human being could cope with this without his help" (Interview).

She feels that she has learned to be more patient, and now does not want anybody to be pity her. Since the loss she feels she has had a lot of sickness and now suffers from arthritis.

When asked whether she has ever felt suicidal she replies negatively but expresses that she would like to die but not by taking her own life.

At the end of the interview Janette expressed her thankfulness at being able to talk about her sons.

General Reflections on Experience in Beirut, Lebanon, 1996

Three areas of understanding emerged as a result of this visit.

1. There was a customary form of ritual associated with bereavement, irrespective of the war situation. Initially, straight after the death there was a time of wailing by the parent. The funeral would take place within twenty four hours of the death if at all possible. This was followed by the family opening their home for visitors to come and give their respects. This involved the Mother usually telling the story of events to the visitors. She could end up repeating this account many times over a short period. The family would wear black clothes as far as possible and the mother would remain in black for some time afterwards. Although in the first week the family would be very supportive and open about talking about the death, afterwards Mothers particularly felt they lacked the opportunity to talk about their loss to family and friends.
2. Parents showed signs of grief over a period of at least eleven years. This involved the parent daily remembering the child, maintaining a prominent position of photographs of the deceased in their homes, and regularly visiting the grave side.

There were also visible signs of the parents showing emotion and tears during the interview as they told their story.

3. The war time context of the death added to the intensity of the grief that followed.

There was an ever-present sign of previous wars by the state of the surrounding area. This proved to be a constant reminder of the parents loss. Due to the recent bombing there was also an increasing fear within people that more deaths could occur. This raised the fear already in the parents for the safety of their remaining children. Although most people had experienced loss of relatives over the recent years due to war, those interviewed still felt very alone in their grief experience.

This study took place in an unusual circumstance. The noise of gun fire and the pictures on local television of deaths by the bombing that took place over the ten days in which the interviewing was carried out, added to the intensity of the interview. Nevertheless there did appear to be other clear signs that bereaved parent's lives had not returned to normality after the death of their children. Although the number of interviews were small, they showed that bonding with the deceased seemed to be continuing. A more in-depth and extensive series of interviews was needed to see whether what was conceptualised as shadow grief was present in people's lives irrespective of their culture or religious belief.

MASHALI YAHUSUYO MSIBA.

1. JINA.....NE/KE
2. UMRI
3. JUMLA YA MATOTO WALIO HAI/MATOTO WALIO HAI 0 1 2-3 4+
4. JINA LA MTOTO ALIYEFARIKI
5. UMRI WA MTOTO ALIPOFARIKI Ktk ujauzito 0-2 3-10 11-17 18+
6. MUDA TANGU ALIPOFARIKI 0-2 3-5 6-10 10+
7. AINA YA KIFO UGOMUWA AJALI UAMA JIUA
8. MUDA WA KIFO GHAFLA SAA 24 SIKU 1-7 SIKU 7+
9. MATOTO MANGAPI WALIOZALIWA BAADA YA KIFO
10. HANI Mwingine aliyeferiki katika familia
11. walifarikije
12. Mwanao alikufaje

BAADA YA KIFO SASA

13. BADO UNASIKIA UNYONGE/UCHUNGU /UCHAVU /UCHOSHI
14. JE UMEJISIKIA VIBAYA TANGU KIFO
15. UNAYO MAUMIVU/UCHUNGU
16. UNAYO MAUMIVU KIFUANI
17. UNAKOSA NGUVU
18. JE UNAUMWA NA KICHWA
19. KIFO HICHO KIMEATHIRI HAMU YAKO YA CHAKULA
20. JE UNALO TATIZO LA USINGIZI
21. UNAPATA SHIDA KULALA
22. HUPATA TAABU KUENDELEA KULALA
23. UNAAMKA MAPEWA ZAIDI SASA KULIKO KABLA YA KIFO
24. AFYA YAKO IMEATHIRIWAJE NA KIFO HICHO

25. UNAO MFADHAIKO ZAIDI SASA KULIKO KABLA YA KIFO
26. NI TATIZO GANI HASA LINALOKUSUMBUA
27. UMEWEZA KUSTAHIMILI MSIBA WAKO *lit: are you able to put up with your loss?*
28. JE UNAMWAZIA HUYO MTOTO ALIYEFARIKI
29. UNAHOFIA KWAMBA WENGINE NAO WATAFARIKI
30. JE HOFU YAKO IMEONGEZEKA KUHUSU WANAO WENGINE
31. UNAJISIKIA JE WAKATI UNAPOKUWA UMEJIBURUDISHA
32. NI KOSA LA NANI LILILOSABABISHA KIFO/NANI ANAYESTAHILI KULAUMIWA
33. UMEJIWA NA WAZO LA KUTOTAKA KUISHI
34. JE HISIA ZAKO HUBADILIKA BADILIKA
35. LINI HASA UNAJISIKIA UNAKASIRIKA
36. UMEWAHI KUJISIKIA KAMA UNATAKA KUJARIBU/KUVUNJA-VUNJA VITU
37. UMEWAHI KUJISIKIA KAMA UNATAKA KUWADHURU WATU
38. WAZEZA KUUTAWALA UCHUNGU WAKO
39. UNAJISIKIAJE UNAPOMFIKIRIA MWANAO
40. NI WAKATI GANI UNAPOKUWA NA HUZUNI BAADA YA KIFO CHA MWANAO
41. NI WAKATI GANI HASA BAADA YA KIFO UNAPOJISIKIA VIZURI
42. KUNA WAKATI MAALUMU AMBAO NI MGUMU ZAIDI
43. UMEWAHI KUMWOTA MWANAO
44. NI NDOOTO NZURI AU NDOOTO MBAYA
45. UNAJISIKIAJE BAADA YA NDOOTO HIZO
46. JE UNALIA MPAKA SASA KUHUSU KIFO CHA MWANAO
47. UNAFIKIRIA KUHUSU KIFO CHAKO MWENYewe
48. UNAFIKIRIA MAHALI ALIPO MWANAO SASA
49. UNGEKITAMANI KUWA NA MWANAO HAPA
UNGEKITAMANI
50. UMEWAHI KUONA /KUSIKIA UWEPO WA MWANAO
UNGEKITAMANI

51. JE WATU WANAZUNGUMZA Nawe HABARI ZA MWANAO
52. JE UNAWASIMULIA WATU HABARI ZA MWANAO
53. NI NANI ANAYEKUSIKILIZA/KUKUELEWA
54. NANI ALIYEKUSAIDIA ZAIDI WAKATI WA KIFO/MSIBA
55. NI NANI ANAYEKUSAIDIA KWA SASA
56. FAMILIA YAKO ILIUPOKEAJE MSIBA WA KIFO CHA MWANAO
57. KIFAMILIA MMEFUNGAMANA ZAIDI AU MMEDHOOF^ISHWA KUTOKANA NA KIFO HICHO_L
58. JUMUIYA ILIUPOKEAJE MSIBA HUO
59. UNAFARIJIKA KWAMBA HATA WENGINE PIA WAMEPATA KUFUWA NA MTOTO
60. UNAJISIKIAJE UNAPOONA WATOTO WENYE UMRI SAWA NA MWANAO ALIYEFARIKI
61. JE ULIUSHIKA/GUSA MWILI WA MWANAO MAREHEMU
62. NI AINA GANI YA SHEREHE YA KIDINI ULIYOFANYA KWA AJILI YA MWANAO
63. WAKINA NANI WALIOKUSAIDIA WAKATI WA MAZISHI
64. ULIPENDELEA WATU WENGINE WAMUONE MAREHEMU MWANAO
65. NI JAMBO GANI LILILOKUSAIDIA WAKATI WA MAZISHI
66. NI JAMBO GANI HUKUPENDELEA
67. ULIPATA AINA YA MAZISHI ULIYOTAZAMIA
68. UNAHUDHURIA KWENYE MAZISHI YA WATOTO
69. UNAJISIKIAJE UNAPOKUWAPO
70. MWANAO YUKO WAPI SASA
71. JE UNAAMINI UTAMWONA TENA MWANAO
72. NI KOSA LA NANI LILIFOFANYA MWANAO KUFA
73. JE UNAAMINI MUNGU YEYOTE
74. IMANI YAKO KWA MUNGU IMEBADILIKA
75. IKIWA HUMWAMINI MUNGU, UNAAMINI KITU GANI
76. UNATARAJIA KUMWONA TENA MWANAO
77. NI KWA KIASI GANI MAISHA YAKO YAMEBADILIKA TANGU KIFO CHA MWANAO
78. UMEBADILISHA MISIMAMO MUHIMU
79. KIMELETA BADILIKO LA MAHUSIANO YAKO NA WANAO WENGINE

80. KIFO HICHO KIMELETA BADILIKO LA UHUSIANO WAKO NA WATU WENGINE
81. NI JAMBO GANI ULILOJIFUNZA KUHUSU MAISHA
82. NI JAMBO GANI ULILOJIFUNZA KUHUSU KIFO
83. UTAWAAMBIA NINI WENGINE WALIOFIWA NA MTOTO
84. UMEIMARIKA/AU KUDHOOFIKA KWA SABABU YA MSIBA HUO
85. KUNA TUKIO BAYA LILILOKUPATA TANGU KIFO HICHO
JE HUZUNGUMZA NA MAREHEMU MWANAO
86. UNA SHAUKU YA MAHALI ALIPO SASA
87. UNATAFITI SABABU ZILIZOMFANYA AFE
88. UNAPENDELEA KUMUOTA MWANAO
89. UNAVYO VITU AMBAVYO NI MALI YA MWANAO
90. UMEJARIBU KUWASILIANA NA MWANAO
91. UNAWALEA WATOTO WAKO KWA NJIA TOFAUTI BAADA YA MWANAO KUFARIKI
92. JE NI FARAJA KWAKO KWAMBA WANAKUZUNGUKA NAO PIA WAMEPOTEZA WATOTO
93. NI MAMBO YAPI YA MAANA YALIYOJITOKEZA KWA SABABU YA KIFO CHA MWANAO
94. HEBU NIAMBIE JAMBO LA KUPENDEZA UNALOLIKUMBUKA KUHUSU MWANAO
95. HEBU NIAMBIE JAMBO MOJA ZURI LILILOTOKEA TOKEA WAKATI HUO

1. NAME	M/F	1 2
2. AGE	10-20 21-30 31-40 41-51 51+	1 2 3 4 5
3. STATE	SINGLE PARTNER MULT-PARTNER WIDOW	1 2 3 4
4. NUMBER OF CHILDREN ALIVE	0 1 2-3 4-6 7-10 11+	1 2 3 4 5 6
5. NAME OF DECEASED CHILD/CHILDREN		
6. CHILD'S AGE AT DEATH	prenatal 0-2 3-10 11-17 18+	1 2 3 4 5
7. TIME SINCE CHILD DIED	0-2 3-5 6-10 10-15 16+	1 2 3 4 5
8. WHEN DID YOU NAME YOUR CHILD	B. BIRTH AT BIR. <6MTH >6MTH	1 2 3 4
9. WHO NAMED THE CHILD	PAR REL OTH	1 2 3
10. TYPE OF DEATH	ILLNESS ACCIDENT MURDER SUICIDE	1 2 3 4
1. PROCESS OF DEATH	SUDDEN 24HRS 1-7DAYS 7DAYS+	1 2 3 4
2. HOW MANY CHILDREN BORN SINCE DEATH	0 1-2 3-5 6+	1 2 3 4
3. WHAT IS THE CLOSEST RELATIVE THAT HAS DIED SINCE		
4. HOW DID THEY DIE		

ANTICIPATION

5. WHO SPENT THE MOST TIME WITH THE CHILD		
6. WHAT PROBLEMS HAD YOU EXPERIENCED BEFORE DEATH (WAR, ILLNESS, FOOD)		1 2 3 4
7. DID YOU EVER EXPECT TO LOSE A CHILD	Y/N/?	1 2 3
8. DID YOU SENSE THIS CHILD WOULD DIE	Y/N	1 2
9. WAS THEIR MEDICAL HELP	Y/N	1 2
10. WHAT KIND OF FAMILY HELP	Y/N	1 2
11. HOW DID YOU FEEL ABOUT YOUR CHILD DYING	ANGRY, ALONE NUMB SAD ?	1 2 3 4 5
12. DID YOU PREPARE WHAT YOU WOULD DO AT DEATH	Y/N/?	1 2 3
13. DID YOU BRING IN A RELIGIOUS LEADER	Y/N	1 2
14. WERE YOU PRESENT AT DEATH	Y/N	1 2
15. WERE YOU ALONE OR WITH OTHERS	Y/N	1 2
16. DID YOU HOLD YOUR DEAD CHILD	Y/N	1 2

27. HOW LONG DID YOU STAY WITH YOUR CHILD	MIN HRS DAYS	1 2 3
28. HOW DID YOU REACT AT THE DEATH	SHOCK NUMB CALM	1 2 3
29. WHO HELPED AT THE TIME OF DEATH	NONE/FAM/FRI/COMU	1 2 3 4
30. WHO HELPED WITH THE FUNERAL	NONE/FAM/FRI/COMU	1 2 3 4
31. WHAT KIND OF CEREMONY DID YOU HAVE		
32. WHAT IN THE FUNERAL HELPED YOU	MIN/PEOP/RIT/?	1 2 3 4
33. COULD YOU AFFORD THE CEROMONY YOU WANTED	Y/N	1 2
34. DID YOU WANT PEOPLE TO SEE THE DEAD CHILD	Y/N	1 2
35. WHAT DID PEOPLE SAY TO YOU		

1ST MONTH

36. WAS IT DIFFICULT TO	A. FALL ASLEEP B. STAY ASLEEP C. WAKE EARLY	1 2 3 4
37. DID YOU FEEL TIRED	Y/N	1 2
38. DID YOU FEEL ANY PHYSICAL PAINS	Y/N	1 2
39. DID YOU FEEL SUICIDAL	Y/N	1 2
40. HOW MUCH DID YOUR FAMILY HELP	NONE/LITT/LOT	1 2 3
41. HOW MUCHDID THE COMMUNITY HELP	NONE/LITT/LOT	1 2 3
42. HOW DID THE RELIGIOUS LEADERS HELP	NONE/LITT/LOT	1 2 3
43. WHOSE FAULT WAS THE DEATH	GOD SPIRIT WORLD NONE	1 2 3 4
44. WHOSE FAULT WAS THE DEATH	SELF RELATIVES NONE	1 2 3 4

AFTER THE FIRST YEAR

45. HOW WAS YOUR HEALTH	GOOD/POOR/NORM	1 2 3
46. HOW MUCH DID YOU THINK ABOUT YOUR CHILD	NON/LITT/LOT/ALL	1 2 3 4
47. HOW DID BITH.UNTV FEST.AFFECT YOU	NONE/LITT/LOT	1 2 3
48. HOW DID IT AFFECT YOUR FEELINGS		
49. DID YOU FEEL PHYSICALLY AGGRESSIVE	Y/N	1 2
50. COULD YOU CONTROL YOUR SADDNESS	Y/N	1 2
51. WHAT WAS THE HARDEST TIME IN THE FIRST YEAR		
52. DID YOU THINK ABOUT YOUR OWN DEATH	Y/N	1 2
53. DID YOU SENSE YOUR CHILDS PRESENCE	Y/N	1 2

54. DID YOU TALK TO YOUR DECEASED CHILD	Y/N	1 2
55. HOW DID YOU FEEL ABOUT YOUR OTHER CHILDREN	>PRO/<PRO/SAME	1 2 3
56. WHO SUPPORTED YOU THE MOST IN THE FIRST YEAR	FAM/FRI/COMU	1 2 3
57. AFTER THE 1ST YR. DID YOU FEEL BETTER	Y/N/SAME	1 2 3
58. HOW DID THE LOSS AFFECT YOU		
59. DID YOU FEAR OTHERS MIGHT DIE	Y/N	1 2
60. DID YOU CHANGE YOUR BEHAVIOUR WITH OTHER CHILDREN	Y/N	1 2
61. DOES IT STILL AFFECT YOU NOW	Y/N	1 2
62. HOW MUCH DO YOU THINK ABOUT YOUR CHILD	NON/LIT/LOT/ALL	1 2 3 4
63. DID YOU WANT MORE CHILDREN	Y/N	1 2
64. HAS ANOTHER CHILD REPLACED THE ONE YOU LOST	Y/N	1 2
65. HAS IT AFFECTED YOUR HEALTH TODAY	Y/N	1 2
66. HAS IT AFFECTED YOUR RELATIONSHIP WITH FAMILY	Y/N	1 2
67. HAS IT AFFECTED YOUR RELATIONSHIP WITH COMMUNITY	Y/N	1 2
68. DO YOU STILL TALK TO YOUR CHILD	Y/N	1 2
69. DO YOU STILL HAVE POSSESSIONS OF CHILD	Y/N	1 2
70. HAS YOUR VIEW OF GOD CHANGED	Y/N/INC/DEC	1 2 3 4
71. WHAT ARE THE MAIN PROBLEMS THAT YOU HAVE TODAY		
72. ARE YOU ABLE TO COPE WITH YOUR LOSS	Y/N	1 2
73. WHO DO YOU BLAME FOR THE LOSS		
74. CAN YOU STILL BE SAD	Y/N	1 2
75. DO YOU THINK ABOUT WHERE YOUR CHILD IS NOW	Y/N	1 2
76. DO YOU LONG FOR THE CHILD TO BE WITH YOU NOW	Y/N	1 2
77. DO YOU EVER FEEL SUICIDAL	Y/N	1 2
78. DO PEOPLE TALK ABOUT THE CHILD	Y/N	1 2
79. WOULD YOU LIKE PEOPLE TO SPEAK ABOUT YOUR CHILD	Y/N	1 2
80. DO PEOPLE AVOID YOU BECAUSE OF YOUR LOSS	Y/N	1 2
81. DOES IT HELP THAT OTHERS AROUND YOU HAVE ALSO HAD LOSS	Y/N	1 2
82. HOW DO YOU FEEL WHEN YOU SEE CHILDREN AT THE AGE WHEN YOUR CHILD DIED	OK/SAD/POS	1 2 3

33. HOW DO YOU FEEL WHEN YOU SEE CHILDREN WHO AT THE AGE YOUR CHILD WOULD HAVE BEEN				
TODAY	OK/SAD/POS		1 2 3	
34. DO YOU GO TO FUNERALS OF CHILDREN	Y/N		1 2	
35. DO YOU STILL HAVE BAD DAYS	Y/N		1 2	
36. WHERE IS YOUR CHILD NOW	HEAV/HERE/?		1 2 3	
37. CAN YOU PICTURE HIM/HER	Y/N		1 2	
38. WHAT KIND OF GOD DO YOU BELIEVE IN				
39. HAS ANY GOOD THINGS RESULTED BECAUSE OF THE DEATH	Y/N		1 2	
40. HAS IT AFFECTED YOUR CHARACTER	Y/N		1 2	
41. HAVE YOU CHANGED YOUR BEHAVIOUR/ATTITUDE /WAY YOU THINK	Y/N		1 2	
42. WHAT IS YOUR BEST MEMMMORY OF YOUR CHILD				
43. WHAT ONE GOOD THING HAS HAPPENNED TO YOU RECENTLY				

13. INTERVIEW OF LELO -KAGANDO HOSPITAL,UGANDA,

FRIDAY 6TH JUNE 97

Lelo was a forty eight year old man who worked in the hospital as a security guard. He was married with thirteen living children. Six years ago he and his wife lost two children, twins, through illness. He was interviewed using an interpreter in the chapel office next to the hospital. Lelo had just finished his daily duty on security. This was a dangerous job as rebel activity in the area had recently caused the death of two hospital guards. Over a hundred people had been killed within the previous month. So tension in the neighbourhood was high at this time.

Lelo lived in a typical home within the community, a mud- built two roomed house on a piece of land that he used to grow crops to support his family. Although the father said he loved his children, practically he spent little time with them. This was usual in this community with the mothers meeting most of the needs of the children. From the moment of birth, a mother would carry a baby on her back most of the day while she carried out her usual duties. After the birth of the twins Lelo was called away from home by the government to join the army during a time of civil unrest within the country. This resulted in Lelo not being able to earn a wage or be able to till his land for food for his family. By the time he returned home the twins were six months old . The mother had been unable to find enough food for her family of

thirteen which resulted in the twins being malnourished. By the time the father carried the children a journey of one hour to the hospital, the twins were extremely weak. Days later the first twin died.

Lelo had never expected to lose a child despite the high mortality of children in this area. There is a tradition within parts of Africa that if one twin dies then the other twin will follow its partner shortly afterwards. Lelo waited at the hospital expecting the second child to die. Twenty four hours later both twins had died. The local Christian Chaplain came and prayed for the twins and family. Lelo held his children and cried. Thirty minutes later he was carrying his children home in his arms.

His wife on seeing the twins began to cry and wail outside the house for four hours. The next day the twins were buried on Lelo's land with a local priest performing a Christian burial. The children were laid on the ground for family and neighbours to be able to see and give their respects. However several people did not look or even kept away from the funeral. At this time within the community people believed that to give birth to twins was bad luck. At funerals it is the duty of the bereaved family to provide food for all those who attend the funeral. Due to Lelo's poverty he was unable to provide food which was resented by some of the community. The reaction of his friends and neighbours was very mixed. Some echoed their Christian faith by telling Lelo to stand firm in his faith. Others said it was his own fault for having twins. Some joked with him that he should have provided food for he could not be poor if he had

twins. Lelo felt extremely angry but kept his feelings within. Now six years later he can still feel angry at how people reacted.

The next day relatives and friends had all gone back to their homes expecting Lelo's family to get back on with their lives. But unfortunately within two weeks Lelo's only goat had been stolen and his house had blown down . Lelo went to get support from the community chiefs but they refused. In the days that followed Lelo was extremely angry. He blamed the community for not supporting him better and the government for taking him away from his family. However his biggest anger focused upon himself. He felt it was his fault for allowing his children to starve. He blamed himself for not being wealthy enough to feed people and constantly asked God what he must have done to be punished in this way.

Lelo acknowledged that he thought a lot about the twins in the first year of grief. Even six years later he says he still thinks about and pictures them. He regrets not having any possessions that belonged to the twins. However one of his surviving children looks like one of the twins which constantly reminds him of his loss. When ever he has extra cash he buys something for the family as a reminder of his dead children.

Over the first year people in the community would not associate with him or shake hands believing he was bad luck or that a curse had been put upon him. His uncle, who was not afraid of the concept of ' bad luck' began to negotiate with Lelo's neighbours trying to make life a little easier for the Lelo household.

Lelo felt that his life would be taken next by God, increasing his worry for his family. He would often feel and sense the presence of the twins even up to today. He would also dream about the children. In the dream he would only see the backs of the twins which upset him as he wanted to see their faces. In the dream when he tries to see their faces the twins turn away from him. But he was glad to dream about them as it made him feel close to the children. It also meant that he believed that they were still alive in some sense, otherwise they would not be able to turn away from him.

Over the last six years he has wanted to talk about his loss but this was the first time someone had asked him directly about it. He was therefore glad to talk. He confessed that he has become more anxious for his other children and increasingly more protective. He is glad to have had two further children born to him. Lelo did not feel this replaced the deceased children in any way. Children in his community are named in the sequence that they are born in e.g. first child, second child. This does mean that a baby is never renamed after a deceased child. It also means that in the list of names a parent has for their children, they can clearly see if a child is missing.

Over the last six years other members of the community have also given birth to twins. This has eased the pressure upon the Lelo's family in their relationships with other people. However Lelo would prefer people to talk more about his loss. Lelo

believes the children are now part of the 'living dead'. He believes that he will see them again in heaven. He does not have bad days any more but he continues to remember the children. This particularly comes to him when he attends other funerals or when his children are ill. He also sees children who are the same age as the twins would be today. This saddens him greatly. Since the twins were buried upon his own land he is able to see the burial site daily as he cares for the land.

Lelo is at least proud that he has not lost his Christian faith. People had encouraged him to go to the medicine man to release his family from a curse but he had refused. He says his faith is now firmer as he still depends upon God for the well being of his family. He feels he has become more patient since the loss and more caring towards the family. Lelo is now in paid work which has enabled him to rebuild his house and feed his family. He worries that that he could easily lose his job but while employed he tries to save his money. He particularly wants to be able to buy another goat so that if another death does ever occur, he would be able to feed all the visitors.

Lelo said he was grateful to be able to talk about his loss and to particularly be able to express his feelings. At times in the interview he looked tearful but did not cry. The interview took one and a half hours.

14. INTERVIEW WITH KELLY, MOSHI, TANZANIA 9TH JULY 97

Kelly was a forty two year old Baptist pastor in one of the larger towns in Tanzania. He was married with two living children. The interview took place in his house in English without an interpreter.

In 1989 Kelly's second child was killed at the age of six by an accident. At the time Kelly and his wife were living away from his family at theological college. His son was playing on a wall from which he fell and landed onto some broken bricks. As the boy fell he broke his neck. However the family did not realise this so did not get a doctor till the following day. They managed then to get him to hospital where his dad stayed with him . Kelly believed that the hospital care was very poor due to a shortage of money in the hospital.

Two days later the boy died. The father was with the boy holding his hand at the point of death. Kelly was so distraught that he fainted. When he recovered it was his task to inform his wife.

Normally in Kelly's home community, the child would be buried on one's own land near the house. It was believed that by being buried close to one's home the deceased would keep evil spirits away. Sometimes, brewed beer would be poured onto the grave to protect the deceased child. Also coffee beans would be thrown onto the

grave as a sign of accepting the spirit into their home. However in this case, since they lived away from home, the child was buried at the local cemetery.

Tradition says that unless the child is buried at the fathers home , then the child's spirit can not be with the other deceased relatives, and can therefore not be part of the family. When the extended family were informed, arguments took place about how the child should be buried. Both Kelly and his wife were from Muslim families. Kelly's wife refused to go to the funeral and cemetery because a relative told her that her deceased child must have been bewitched. She left her husband in her anger and grief and her relatives took her to see a medicine man to remove the curse. A month later she returned to her husband and have been together ever since.

Kelly's wife began by sitting in on the interview but she soon looked upset and so she left the room. Within this particular community in Tanzania as compared to Uganda, the relatives do not cry outwardly or wail . So at the funeral there was only a little crying by Kelly's relatives. Kelly himself didn't cry. His family came and stayed in his home. Usually the relatives would all stay and take over all the arrangements for the funeral as well as the hospitality to visitors. Kelly did not feel afraid at the funeral but he did feel afraid afterwards to go to the burial site. At this point Kelly began to cry in the interview.

Kelly saw a psychiatrist daily after the death. He would cry daily and visit the grave. At times he would refuse to believe that the boy had died. He felt his world had ended and expressed how he could have easily committed suicide. The marriage was extremely difficult at this time. Kelly's wife blamed him for not getting the doctor sooner. She also resented the fact that they were away from their family home and Perry had to be buried in a cemetery. They were also fearful of attempting to have another child as the last birth was by caesarean delivery which in a Tanzanian hospital carries greater risk. Months after the death their older daughter fell and cut her head. People around saw this as a sign that the family were cursed.

Kelly felt that in the first year of loss his whole family became depressed. He himself stopped eating and lost weight.

" I was thinking, thinking, thinking, Does God care?"

Kelly had had a tough upbringing which led him to running away and becoming addicted to drugs. His life had changed radically since becoming a Christian and getting married. But the death of his son brought back many memories of his past. When his wife blamed him he felt like running away again and taking his life. He had changed jobs and it was costly to train to be a pastor, Kelly began to wonder whether God wanted him to be a pastor. Kelly would have days of wanting to be alone and not share his thoughts with anyone.

" I would go on a five mile walk by myself, and keep saying to myself, 'I'm worth nothing'. "

Being educated, Kelly was able to be more aware of anniversary dates and thus found Christmas , birthdays and Perry's burial day difficult times. Although the father did not believe in the ' living dead' concept he did sense his son's presence in the early months of bereavement. Kelly acknowledged that even now he could find himself during a meal time being suddenly hit with thoughts of 'Why.'

Since then the couple have had another child , a girl born in 1992, 3 years after the death of Perry. They called her Terry deliberately since there was only one letter different from their sons name. His older, twelve year old daughter recently said, " Perry would be 14 now."

Kelly's family does not live in the same area any longer but he does travel back to visit the grave when he can afford the travel costs. Perry's parents are more protective to their remaining two children. As I was interviewing, their oldest daughter of twelve was travelling alone to visit her grandmother. Children normally travel alone at an earlier age than this but her parents were clearly worried about the trip.

Kelly finds it a comfort that so many people in his community have also had loss in their lives. he now feels better equipped to be able to help others in their loss. He still believes in God but is more aware of the fragility of life. He believes his son is in

heaven and will one day be united with him. Kelly can now think about his son more positively than previously. Previously, when he thought about his son he felt he would be swallowed up by death thoughts.

" While he was apart of us I could help him, but now there is nothing I can do for him."

Now Kelly felt able to get on with his life but the shadow of his loss was clearly evident. Several times in the interview Kelly had to pause to control his crying. He seemed grateful for having the opportunity to talk and regrets not having the opportunity to do so more often. He seldom talks to his wife about their pain as his wife is unwilling to raise the issue. Kelly particularly wanted to know whether his experience was any different from other bereaved parents. The interview took two hours.

15. INTERVIEWING THE MASAI TRIBE

The three interviews took place individually in the parent's home which were called Bomas. They consisted of a cow dung hut with no windows or gaps for light to enter. The only form of light came from the remains of ashes from a fire used during the night. During the interview, the parent would continue to perform their routine duties of cleaning their milk gourd or drinking a milk type tea. The interviews consisted of talking to the community leader who had lost a 17 year old son nineteen years ago, a grandmother who had lost a daughter aged 23 two years previous, and another mother who had lost a 28 year old daughter four years ago. The boy was killed in a lion hunt while the girls died due to illness.

Generally the Masai did not expect to lose children. However the older teenage boys are sent out into the bush to earn their manhood by killing lions. It is not unusual for some of these teenagers to be killed or to end up killing each other in the process of being recognised as a man of the community.

Surprisingly in all three situations the deceased had received medical attention, and two had attended hospital although clearly too late to alter the situation. Both the girls who died left babies now looked after by the grandmothers. In all cases the bereaved touched the deceased as little as possible. The boy was given a typical Masai funeral which is to leave his body outside the Kraal camp for the hyenas or other

animals to remove. Daily the body is checked until it is removed or devoured by the animals. In the case of the girls they received a Christian burial and were given a grave outside the camp. The grave site was not visited. The Masai do cry and express their grief at death but not to the same extent as the other communities interviewed.

Mothers expressed the opinion that crying did not help the situation.

However from the bereaved Masai who were interviewed, as well as talking to other members of the communities, it was clear that anger was very present within the people. It seemed that the deaths were seen as a form of punishment of some kind although the reason for such punishment was unclear in the minds of the bereaved.

When asked about their feelings of anger, it seemed that although they acknowledged this emotion, it was unclear who it was addressed towards or whether it was ever expressed within the community. It may be that the men of the community might well have answered this question in a different way to the women, especially since the men are able to express more emotion in their rites of passage to manhood.

The community was supportive initially by sharing their condolences and bringing gifts of money, cloth and food. However after this point neither the bereaved nor the community talked about their loss. Yet everyday there is a constant reminder of the community's loss by the way the people dress. It is custom for a member of the Masai to always wear cloth coloured red as a sign of respect for the dead. This is not something that is worn for a short period of time as a form of short mourning but is in fact the custom dress of all Masai throughout their lives. The

concept is related mainly to the boys who go out into the bush as part of their rite of passage to manhood and risk their lives in killing lions. The red reminds the community of those who never return. The colour of the clothe can also remind the community of other types of losses.

The bereaved all reported that they did dream about the deceased and that this was generally seen as being a positive experience. Parents, whether Christian or non Christian, said that they had no hope or belief of ever seeing their child again. They believed that the spirit of the deceased had departed for a place that they would never see. The bereaved were unclear as to whether they thought their spirit would go to the same place as the deceased child. In such a basic society all possessions were reused within the community except for any bracelets which the parents had kept as special. The thought of talking about their deceased seemed strange to the Masai and recognised as a painful thing to do, even for the father after nineteen years. As one Masai put it,

" It is better not to talk about the loss as you never get over it" (Interview).

The Masai did express how their loss made them more caring to their remaining children and better able to care for others in their grief. However the mothers particularly found the constant presence of the grandchild a constant reminder of their deceased daughter.

The only evidence for long term grieving within the Masai came from the single interview with the community leader. However there is no reason to doubt that the Masai in general experienced long term grief.